The pharmacological management of palliative care symptoms in haematology and oncology patients at Parirenyatwa Group of Hospitals (PGH) in Harare Zimbabwe.

University of Cape Town

Department of Palliative Medicine

RESEARCH DISSERTATION

DISSERTATION IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR MPHIL IN PALLIATIVE MEDICINE

Name: Agnes Chipo Tererai

Student Number: TRRAGN001

Supervisor: Dr Alan Barnard, UCT

Co-Supervisor: Dr Nomsa Tsikai, UZ

DECLARATION

I, AGNES CHIPO TERERAI, hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

I empower the university to reproduce for the purpose of research either the whole or any portion of the contents in any manner whatsoever.

Signature: Signed by candidate

Date: 13/10/2020

Dedication

To all those who have passed through my care, who have shared their physical, psycho-social and spiritual journeys with me, and whose quality of life improved through access to holistic palliative care.

Acknowledgement

I am grateful to my supervisor, Dr Alan Barnard, for your patience with me, constructive criticism and for your encouraging words especially when I felt like giving up. Your gentle suggestions to seek expert help on writing skills helped me to reach out for guidance.

Dr Nomsa Tsikai, my co-supervisor, thank you for your guidance especially at the beginnings of this project when I needed guidance on how to come up with a good research and critically going through the final work.

Thank you to Dr Liz Gwyther, the UCT MPhil in Palliative Care Coordinator, for providing links and other resources to seek help from during the write-up period. Naomi Fray, your assistance with administrative matters is greatly appreciated.

Dr Gilbert Mardai SJ, thank you for your skilful help in reviewing parts of the write-up, correcting grammar and helping with the coherence and flow of the work, and for encouraging me to soldier on and to see the potential in me.

I am grateful to Laura Milne for your assistance at the end in connecting the loose ends and making the work presentable.

My colleague, Dr Dickson Chifamba, thank you for your mentorship and dedication in making palliative care in Zimbabwe gain support from all stakeholders.

A big thank you to my Dominican Sisters Community at Emerald Hill Harare, for bearing with me, understanding my long working nights, and listening to my stories with interest and support.

To my parents, siblings, entire clan and friends, your presence continues to give me the reason to value multidisciplinary approach in the care of my patients as you all represent that unique part of the puzzle without which the picture is not complete.

Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
BNF	British National Formulary
EDLIZ	Essential Drug List in Zimbabwe
ESAS	Edmonton Symptom Assessment Scale
HIV	Human Immunodeficiency Virus
HMO	Haematology and Medical Oncology
HREC	Human Research Ethics Committee
HOSPAZ	Hospice and Palliative Care Association of Zimbabwe
IAHPC	International Association of Hospice and Palliative Care
LIC	Low income countries
IPOS	Integrated Palliative care Outcome Scale
LMIC	Low to middle income countries
MCAZ	Medicines Control Authority of Zimbabwe
MRCZ	Medical Research Council of Zimbabwe
MDT	Multidisciplinary Team
MMR	Mixed Methods Research
NCCN	National Comprehensive Cancer Network
NCDs	Non-communicable diseases
NGO	Non-governmental organisation
NSAIDs	Non-steroidal anti-inflammatory drugs
PC	Palliative Care

PCA	Patient-controlled analgesia
PGH	Parirenyatwa Group of Hospitals
PHS	Public Health Strategy
SDG	Sustainable Development Goal
SPSS	Social Package for Social Sciences
SSA	Sub-Sahara Africa
UCT	University of Cape Town
UHC	Universal Health Coverage
UK	United Kingdom
UN	United Nations
USB	Universal Serial Bus
WHA	World Health Assembly
WHO	World Health Organization

Contents

Abstract

Introduction: Palliative care is the approach to the care of patients with life-threatening illnesses. An important part of this is the rational use of a pharmacological approach to relieve suffering by addressing the symptom burden of the patient. Palliative care symptoms contribute a great deal to the suffering of the patient and affects quality of life. Different studies across several countries on the palliative care symptoms have identified common symptoms with pain being the most frequent. The WHO Public Health Strategy for palliative care outlines four components: policy, education, implementation and drug availability. These components interlink and each one affects the others. The drugs used for palliative care symptoms should be classified as essential medicines and be available to all patients who need this treatment. Factors influencing the effective pharmacological management of palliative care symptoms include drug availability, policy and the approach of the prescribers. Studies have shown that developing countries rank low in the use of the essential palliative care drugs especially morphine.

Aim: The aim of this study was to describe the prevalence of palliative care symptoms and the prescribing and administration patterns in oncology and haematology patients at PGH, as well as exploring the health workers' opinions on the pharmacological approach to these symptoms.

Methods: A mixed method approach was used to qualitatively look at the health workers' responses using inductive thematic analysis and quantitatively obtain information on palliative care symptom management from the health workers and patient records.

Results: Pain was the commonest palliative care symptom identified by health workers, and evident in the patient records. A list of other palliative care symptoms, and the frequency at which they occurred was compiled in this study. The health workers highlighted drug availability, palliative care education and need to engage some nurses in prescribing some of the palliative care drugs. Fewer than half of the patient records assessed as being in need of palliative care (N = 247) were given medications from the recognized palliative care drug list (N = 101).

Conclusion: This study showed that essential medicines for palliative care symptoms are not easily available in Zimbabwe for various reasons that include cost, policy, education and training. Pain and other palliative care symptoms are not adequately managed. Therefore; palliative care is not yet integrated into the health care system in Zimbabwe as mandated by the WHO. Recommendations to improve palliative care symptom treatment are suggested.

Key words: palliative care symptoms, prescribing, availability, management, medicines/drugs, health workers

1. Introduction

Palliative care practice and services are an important part of public health practices and policies around the world; understanding how health care workers treat patients in their care can help explore the challenges and room for growth in local contexts. It is widely acknowledged that there is a need for improved palliative care services in Zimbabwe and similar Low Income Countries (LIC) and Low to Middle Income Countries (LMIC) contexts (1-4). The Lancet Commission on Palliative Care and Pain Relief showed that 25.5 of 56.2 million deaths in 2015 were associated with serious health-related suffering and more than 80% of the 61 million people with conditions requiring palliative care live in LMICs (1). As is reported in the Zimbabwe National Palliative Care Policy (Hospaz.co.zw, 2020), in this context, patients suffer due to conditions such as cancers and HIV/AIDS, which may cause premature loss of life (5). The palliative care needs for Zimbabweans was estimated at 1 in 60 in a World Health Organisation (WHO) initiated study done in 2004 which looked at 5 countries inclusive of Zimbabwe (6). The purpose of this research is to better understand local palliative care practice. By better understanding the palliative care practice in the Zimbabwean context, health care workers' actions and opinions can feed back into future policy and recommendations.

The need for palliative care services requires robust evidence to persuade health departments and health care providers to meet that need and fulfil the obligation that the World Health Assembly (WHA) Declaration of 2014 requires of all nations that are signatories to the WHO (4). The Zimbabwe National Palliative Care Policy states that "operational research should be conducted to improve evidence for palliative care services and to identify best practice models" (5). As efforts to integrate palliative care into the health care system for the whole country of Zimbabwe are currently in the process, it would be helpful to present local evidence in order to strengthen its acceptance.

In-order to establish the best practice models via research, it is necessary to build an appreciation of palliative care and its components. The WHO definition of palliative care states that "it is an approach that *improves the quality of life* of patients and their families facing the problem associated with *life-threatening illness,* through the *prevention and relief of suffering*

by means of early identification and impeccable assessment and *treatment of pain and other problems,* physical, psychosocial and spiritual" (7). Pain is a common and feared symptom of both cancer and non-malignant life-threatening disease, (8) so pharmacological approaches to pain are among the priority interventions in these patients.

Sub-Saharan Africa (SSA), which comprises many LIC and LMIC countries, has an increasing burden of non-communicable diseases (NCDs) including cancers and cardiovascular diseases which contribute to the need for palliative care in those countries. The increase in NCDs makes a big contribution towards the need for palliative care. In their study, Mufunda and colleagues stated that the burden of disease due to NCDs "is rapidly increasing based on projections made from a limited number of African reports" (9). In the context of HIV illness, such as is found in parts of Africa, Magodoro et al report that NCD risk was higher in persons with HIV, particularly if these persons were older than 50 years (10). This further contributes to the need for palliative care. A study on palliative care in SSA focusing on Uganda, South Africa and Zimbabwe showed the effectiveness of palliative care services, especially in the HIV population (11). While the Lancet report and the Zimbabwe national palliative care policy indicate the need for pain relief, it is important to elicit the views of health workers, who are hands on with the patients, in order to come up with strong supporting information to use in advocating for essential palliative care medicines. Healthcare providers are important in the implementation of any new approach.

A report on research into palliative care in SSA from several palliative care experts, published in the Lancet in 2013, proposed that research be made the fifth pillar within the WHO public health strategy for palliative care (3). The need to include research is necessary to allow for a broader evidence base from within Africa, especially for cancer palliative care due to the projected increase in cancer incidence in the African region, in order to inform best practice (3). Evidence-based information from Africa is necessary accurately to describe palliative care symptomatology and its management (11). Some studies from the African context that have looked into the pharmacological aspects of palliative care focused on a few symptoms related to a limited number of conditions, i.e. HIV/AIDS or a stage of illness, namely the end of

life/terminal stages in palliative care (12-15). One such example reported the study of the "use of sedation for the management of end-of-life shortness of breath and delirium" in a hospice in South Africa (15). The same study highlighted the variability that exists in the management of these symptoms, hence the need for further investigation (15).

This study seeks to add to the evidence base on the current pharmacological management of palliative care symptoms in the African context by conducting a retrospective survey of patient records and obtaining feedback from some of the health workers at Parirenyatwa group of hospitals (PGH) in Harare, Zimbabwe. PGH is one of the few referral hospitals for haematology and oncology patients in Zimbabwe. Though acknowledging that all life-threatening conditions require palliative care, the scope of this study was limited to cancer patients, and the researcher took advantage of the historical evolution of palliative care within and alongside oncology (16) by focusing on palliative care as offered to oncology and haematology patients. The study examined medical records and obtained information from the health workers.

From the palliative care definition, it is imperative that the availability and use of essential palliative care medicines and equipment is made a priority in the national palliative care policies of all countries (17). For a consensus on the essential palliative care medicines and equipment, a list of twenty one common palliative care symptoms was developed first by the IAHPC (International Association of Hospice and Palliative Care Committee) which followed by identifying the medications used to treat these symptoms (18). This process engaged many palliative care leaders from around the world (18).

In this study, a symptom list has been adopted from the findings of Potter et al (19) so that the symptom burden can be correlated with the management of the palliative care patients, especially the prescription of medicines. This symptom list was used as it covered a wide range of the expected symptoms in palliative care. The list enabled health workers in this study to identify what they encounter most in their practice and also helped in identifying palliative care symptoms in the retrospective survey of patient records. The availability and use of pharmacologic agents for palliative care symptoms in Zimbabwe is an area which requires

investigation and documentation especially in the context of current efforts to include palliative care as part of routine patient care

2. Literature review

2.1 Public Health Strategy (PHS)

At the core of this investigation is the place of healthcare workers within the context of public health policy and practice. Public health is defined as the science of protecting the safety and improving the health of communities through education, policy-making and research for disease and injury prevention (20). In 2002, Sepúlveda et al. proposed that "it is essential to promote a public health approach in which comprehensive palliative care programs are integrated into the existing health systems" (21). The WHO further advocates that these programs are implemented in a way that is in keeping with the context of the population for whom they are implemented (21). This is supported by the fact that "the heterogeneity of palliative care populations complicates efforts to generalize from one population to another" as expressed by Currow and colleagues in the *Journal Of Pain And Symptom Management*, 2009 (22). Quality care at end of life is a global public health problem (23, 24), and in the African context this is evident as many people with life-threatening illnesses do not have access to adequate palliative care (21). The WHO public health strategy (PHS) for palliative care encompasses four main domains: Policy, Drug Availability, Education and Implementation (25). Richard Harding and colleagues suggested that the PHS should have a fifth focus area of **research activity** to stimulate improvement of care (3). The importance of public health provision was highlighted by the United Nations' Sustainable Development Goals (SDG). SDG Target 3 includes the following: "*Achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all" (26).* Countries cannot meet Sustainable Development Goal (SDG) Target 3.8 on Universal Health Coverage (UHC) without including palliative care and pain relief (1).

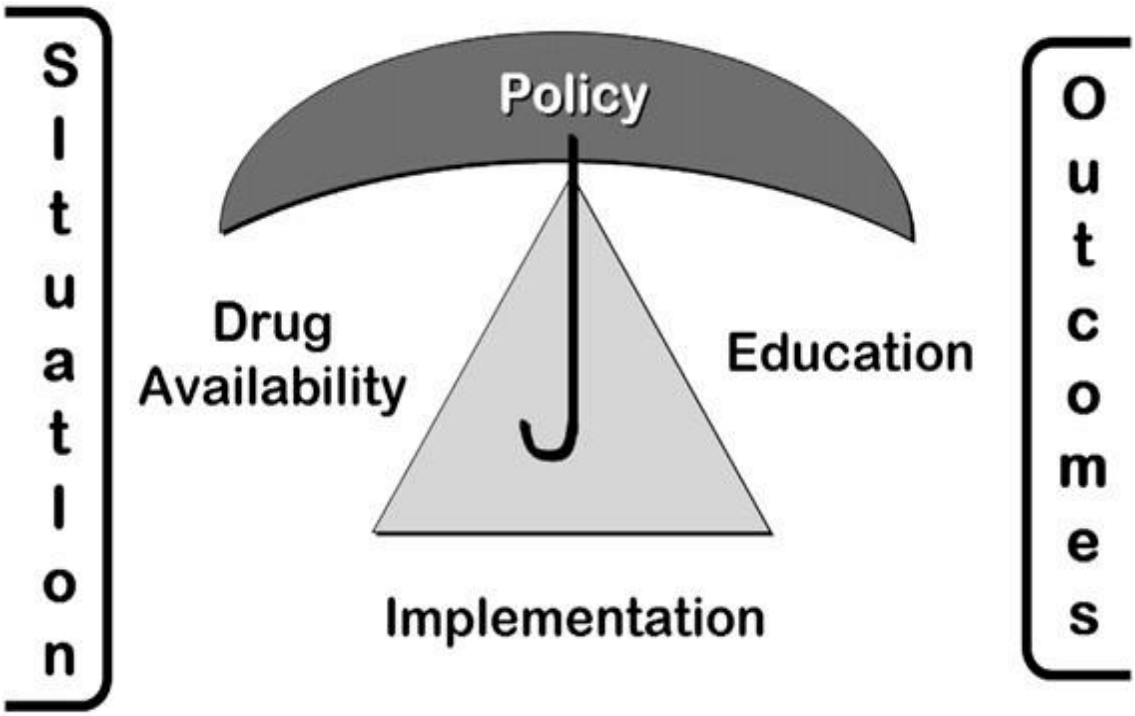


Figure 1: WHO Public Health Model (25)

As can be seen in Figure 1: WHO Public Health Model, underneath the umbrella of policy, according to education, drug availability and implementation of standards of practice, healthcare practitioners bridge the gap between situation and outcomes for patients. All of the elements in the diagram must be held together for successful palliative care approaches, and the purpose of the study is to see how they can be supported through research. This study focuses on one of the domains of the WHO PHS on palliative care (25), namely drug availability. Progress towards palliative care integration in Africa should examine factors influencing the implementation for it to be successful. The public health model gives a pictorial summary of the factors influencing the success of palliative care. Figure 1 above shows that adequate drug availability for palliative care is affected by the policy, associated education and the implementation of the services at all levels. These are interrelated components of the PHS which are mutually interdependent. Due to the interlinking of these areas of focus, it is important to always consider the other aspects as well when looking at one particular area of the strategy.

As WHO continues to emphasize and encourage all countries to integrate palliative care services into their health system, Stjernswärd et al. argue that for the Public Health Strategies to work, governments must incorporate them throughout healthcare and gain acceptance by the communities (25). A study done in 2004 on the health seeking behaviour of HIV/AIDS patients in Malawi revealed that health facilities are usually the last resort for patients who attend the traditional healers and faith healers first (27). The health seeking behaviour of Zimbabweans would be likely to be similar to those of Malawians due to the two countries sharing borders and having similar challenges related to poverty and health care. Low income countries like Zimbabwe and many other African countries also face the challenge of distributive justice in the access to essential palliative care drugs, which in turn has consequences on the patients' quality of life (28). It is in line with this WHA 67.19 declaration on palliative care 2014 (29) that most governments, including Zimbabwe, are integrating palliative care as part of total patient care. When considering drug availability and the policies in place concerning controlled drugs such as opioids, it is important to also consider issues of accessibility and affordability, particularly within a LIC context. The WHA resolutions in 2014 emphasized the PHS focus on drug availability by resolving to "ensure adequate supply of essential medicines in palliative care, avoiding shortages and to improve access and rational use of pain management medicines, in line with the United Nations (UN) international drug control conventions, as well as to update as appropriately the national essential medicines lists" (29).

2.2 Palliative Care Symptoms in Haematology and Oncology Patients

In the past, and even to the present day, cancer in its diversity remains a major life-threatening illness. In 2003, Potter et al. conducted a retrospective study in which they investigated 400 referrals for palliative care in London, of which 95% (380) had a diagnosis of cancer (19); this indicates the comparative impact that public health research into the management of palliative cases could have in the African context. Other conditions, such as HIV/AIDS, increase the cancer burden within developing countries, particularly where certain cancers such as cancer of the cervix and lymphomas are on the rise in HIV/AIDS patients (30). Haematological malignancies and solid tumours require palliative care, as they are all chronic diseases which frequently present with distressing symptoms towards the end of the patient's life. Oncology is

traditionally understood to focus on solid organ cancers, while haematology focuses on both benign and malignant bone marrow, lymphoreticular and blood conditions. The differentiation between these disciplines makes pragmatic sense, as there are distinct diagnostic and therapeutic differences. Palliative care management draws the two together, however, as the symptom burden and psychosocial and spiritual aspects are very similar, independent of the nature of the disease. This was affirmed by the results of a study conducted in 2008 in the United Kingdom (UK) which revealed that patients with haematological conditions had similar problems to those with solid tumours (31). These findings suggest that symptoms which present in palliative care seem to cut across all life-threatening illnesses, and therefore, their management should be part of the consideration for public health policy on palliative care.

In a 2011 study on the prevalence and burden of palliative care symptoms in two African countries, Harding et al. reported that most of the cancer diagnoses in Africa are made when the disease has progressed beyond the stage of possible curative intervention; additionally, there is limited evidence from African contexts regarding the symptom burden in advanced cancers (32). From the various places of care in their London-based study, Potter et al. reported that the key palliative care symptoms are consistently reported, with the main symptoms being pain and weakness/fatigue (19). Harding et al.'s 2011 study in an African context showed a similar trend to Potter's study, whereby "pain, lack of energy, feeling sad, feeling drowsy and worrying" were among the 5 most prevalent symptoms (32). Harding et al.'s study on "the prevalence and burden of symptoms amongst advanced cancer patients attending palliative care" showed that "pain and psychological symptoms were the most common symptoms" (32). In the 1990s it was noted that many patients with cancer or AIDS developed cachexia before death and about 80% of patients with upper gastrointestinal cancers and 60% of lung cancer patients at diagnosis have substantial weight loss (33). A South African study on sedation for uncontrolled symptoms in hospice care of the imminently dying revealed that the major symptoms were pain, nausea, dyspnoea and delirium (15). While studies may differ on what the commonest symptoms in palliative care are, the message which comes across is that patients with life-threatening illnesses experience suffering that alters their quality of life. Taking these studies into account, there is a gap in the literature: there is limited

evidence from research describing the symptomatology and management of patients with life-threatening/life-limiting illnesses in Zimbabwe however.

Palliative care symptoms vary according to the progression of the disease trajectory; several factors can influence what the patient presents with, however an overall analysis of the main symptoms in palliation is important in guiding provision of care and the best approach. The assessment tools must be user-friendly to the patient and the clinician, which will reduce the specific challenge of missing data especially in terminal and end of life stages (34).

The same study by Potter et al. came up with the following twenty-seven palliative care symptoms as shown on Table 1 below, starting with the commonest (19), this provides a wide range of symptoms to act as a guide when assessing patients.

Table 1: Palliative care symptoms listed in order from most frequently reported to least frequently reported (19)

1. Pain	10. Low mood	19. Loose stool
2. Anorexia	11. Vomiting	20. Dyspepsia
3. Constipation	12. Dry mouth	21. Numbness/tingling
4. Weakness	13. Cough	22. Dysphagia
5. Dyspnoea	14. Dermatological	23. Haemorrhage
6. Nausea	15. Urinary	24. Early satiety
7. Neuropsychiatric	16. Anxiety	25. Sweating
8. Tiredness	17. Oedema	26. Hiccoughs
9. Weight loss	18. Sleep problems	27. Taste change

Studies conducted across different geographical and social contexts produced similar lists of palliative care symptoms, meaning it is equally important to consider symptom management

trends, and whether these are applicable to the Zimbabwean context too. It is important in palliative care to emphasize the fact that palliation and curative measures can go hand in hand. Sometimes the patient's quality of life is not met by simply focusing on curative measures, and when this is not possible or not available a "nothing else can be done" attitude seems to overshadow even the basic approaches that can provide comfort and relief to the patient. For example, in the early 2000s when antiretroviral therapy (ART) was not readily available, patients who had AIDS-related symptoms like pain, cough, dyspnoea, diarrhoea, anorexia, nausea, pruritus or malaise would get little attention to relieving these symptoms (35). In the African context, poverty can often be a hindrance to access the curative measures of a life-threatening illness and palliative care can still provide the comfort and relief due to the holistic focus on the patient's needs.

2.3 Pharmacological Management of Palliative Care Symptoms

In 2007, the IAHPC produced a list of essential medicines for palliative care through an extensive process that was led by palliative care experts from across the world (36). The experts encouraged research to provide an evidence base for use of the recommended medications. In 2013, the WHO came up with a list of 15 palliative care and pain medicines based on 11 palliative care symptoms in advanced disease stages and end of life stage (37). According to the WHO, essential medicines are those that satisfy the primary health care needs of the population. This study uses the palliative care medicines/drugs used to manage palliative care symptoms, some of which are not on the above-mentioned list as the WHO list was for a few symptoms. In response to this need to effectively manage palliative care symptoms, many countries are now developing or adding a section on drugs used to manage palliative care symptoms to their existing national drug lists. As palliative care continues to grow as a specialty, more evidence is emerging showing the efficacy of pharmacological interventions for palliative care symptoms. For example, in 2015 a retrospective cohort study at a palliative care centre in the Netherlands showed that at the end of life most patients receive discomfort relieving drugs (38). A recent study conducted in 2018 provided evidence for the pharmacological approach for some palliative care symptoms like breathlessness, delirium, nausea and vomiting, constipation and respiratory secretions (39). All research efforts, including the development and

accumulation of further evidence based on the care of patients requiring drug treatment in palliative care, contributes to further improvement of care.

In Zimbabwe, the 2015 essential drug list has a section on medicines used for pain management in palliative care (40). While having this section on palliative pain management is a commendable step, there are still important gaps which need to be considered. Areas of concern include the management of palliative symptoms other than pain, additional equipment and infrastructure for palliation, and the support and training of professionals for palliative care provision. There is a need, for example, for professionals who are skilled at using subcutaneous infusion pumps in palliative care (so-called *syringe drivers*). The ongoing revision and update of guidelines should include continuity of care, including out of hours care, advanced prescribing (like flexibility of dosing), continuity of supply, and urgent need provision for palliative care needs as they may change even after hours (41).

A key symptom in the literature, which will be a central focus of this study, is the need to manage and control pain, as it is often what the patient often presents with. Several studies have been conducted from different groups of patients at different stages of illnesses looking at the physiologic control of pain (42). Adequate pain assessment in palliative care allows for best practice in the provision of care (43). According to WHO guidelines, the analgesic step ladder approach (first published in 1986) should be used for chronic pain (44).

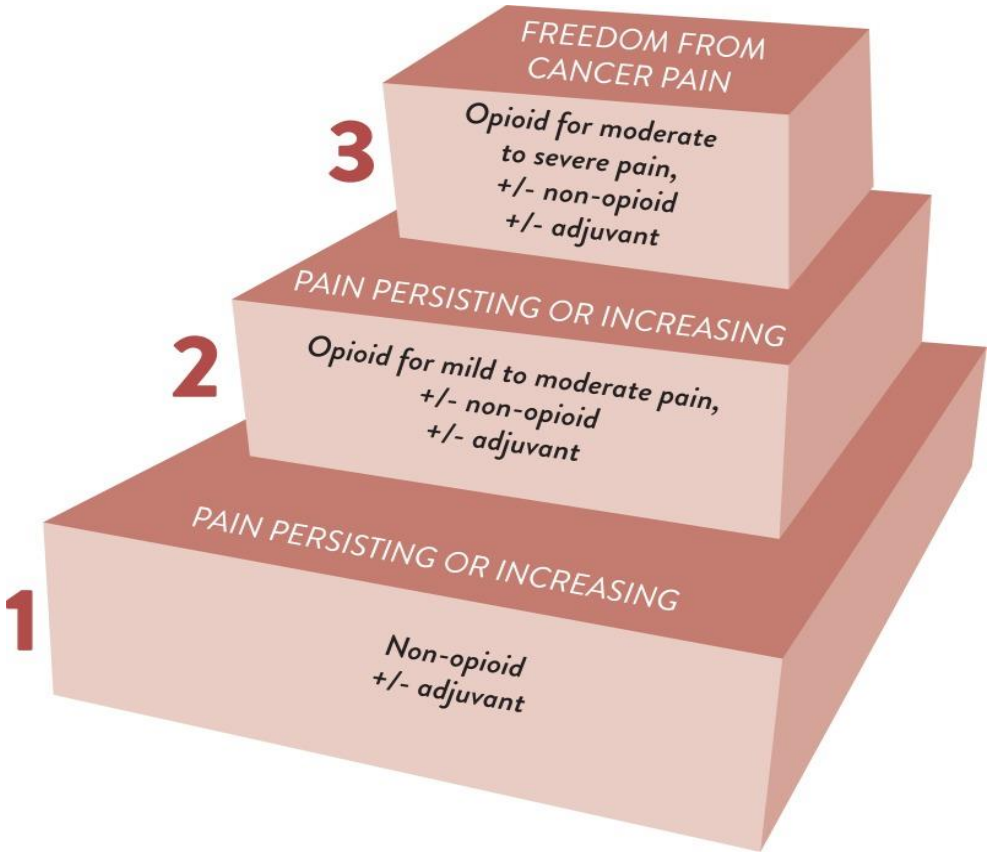


Figure 2: The WHO Analgesic Step Ladder

There are three main principles of the WHO analgesic step ladder, namely "By the clock, by the mouth and by the ladder" (45). "By the clock" means that analgesic drugs should be administered regularly on a fixed schedule depending on the need of the patient and the conditions and the pharmacological properties for the agent. "By the mouth" means that oral administration is preferred in every circumstance unless the patient is unable to swallow or is vomiting. "By the ladder" means that the principles of the WHO analgesic pain ladder be followed with titration of the dose to meet the needs of the patient and the condition. The analgesic step ladder approach should be used starting with simple analgesics such as paracetamol for mild pain, then moderate analgesics or mild opioids such as tramadol and codeine phosphate for moderate pain, followed by strong opioids like morphine for severe pain (46). At each level of pain control, simple analgesics and other co-analgesics like amitriptyline can be given in addition to the pain medications for that level depending on the type of pain the patient is having. This analgesic step ladder has undergone several modifications over the

years to meet the needs for acute and non-cancer pain control as well as reviewing approaches to chronic pain management (44). These modifications have resulted in the addition of a fourth step which encompasses: nerve block, epidurals, patient-controlled analgesia (PCA) pump, neurolytic block therapy and spinal stimulators (46). The basic WHO analgesic step ladder still remains an important template in coming up with practical pain management protocols (44).

Palliative care medicines/drugs in this study refer to the medicines used to manage palliative care symptoms potentially without randomised clinical trials for each symptom to produce supporting evidence for the drug used. The distribution of pain medications among all the countries revealed that Africa had only 0.8% of the share as reported in a study in 2009 on the global distribution of pain medication especially morphine (47). The distribution of these medications is indirectly made worse by certain attitudes towards them for example opiophobia. Opiophobia occurs when people are more concerned about the side effects of the opioid drugs than appreciative of the medical benefits in controlling pain, especially in addressing chronic pain (48). The fears and myths especially on the use of opioids (morphine being the prototype) in managing pain in patients with life-threatening illnesses contribute to the barrier to effective pain control (49). One of the myths in palliative care is the use of injection pethidine as needed whenever patient complains of cancer pain (49). The fact is that, unlike post-surgical pain, cancer pain or chronic pain is not self-limiting nor is it likely to recede spontaneously, but instead it is more likely to increase in intensity and severity (49) hence this discourages pethidine use because of its untoward effects even though it is an opioid. It has been verified that pethidine metabolite norpethidine accumulates in the body with repeated use of pethidine leading to untoward effects such as convulsions especially in the elderly.

As palliative care is a field in its infancy in most developing countries, many gaps exist in all aspects of palliative care, including availability of essential palliative care medications in their different forms. This also calls for continued research at all levels within the developing world if palliative care services have to be well integrated into the health care system.

2.4 Prescribing for Palliative Care Symptoms

There is no local data yet from Zimbabwe to demonstrate the prescription of the listed essential palliative care medicines, especially opioid analgesics, by clinicians, or to discuss the trends that govern these drugs' prescription and use. Prescribing and administration of drugs in palliative care is sometimes ethically difficult due to several reasons for example the timing and selection of outcome measures and the complexity of medication regime at home (50, 51). The prescription of morphine for patients near death and most of the other ethically difficult reasons encountered in palliative care drug prescribing and administration still require extensive discussions as well as support from research. Anderson argues that "applying the principle of double effect to end-of-life issues perpetuates the myth that opioid use at end of life causes respiratory depression and results in the undertreatment of physical suffering at the end of life" (51). Focusing on the local context, efforts are being made understanding drug prescription and administration, especially through collaboration with non-governmental organizations (NGOs) like Island Hospice, a WHO-recognized palliative care demonstration centre that mentors and trains health workers at all levels in palliative care. For particular interest in this study, the NGO trains medical students and specializing doctors on the pharmacological approaches to palliative care symptoms, as well as community health workers who are important in the supervision of the patients taking the medications (52).

While the ethical principles of autonomy, beneficence, non-maleficence, and justice apply across all health practices, there may still be concern and lack of assuredness for practitioners, particularly concerning palliative sedation of terminal patients. Lewis et al. stated in 2010 that the "fear of overuse, misuse, abuse and addiction in prescribing opioid analgesics in patients with chronic pain is one of the major causes of opioid phobia among physicians" (53). Walsh and Hauser stated that in palliative sedation, certain considerations such as which practitioners should be responsible, and the restriction of prescription and administration to licensed palliative medicine specialists, are important ethical considerations (54). Another important consideration when discussing the administration and prescription of important drugs for palliative care patients is which health workers are involved in the process. The health workers in this study included nurses, doctors and pharmacists. The role of pharmacists in palliative care

is more and more being recognized as the inter-disciplinary and multi-disciplinary nature of palliative care continues to unfold (55). In a 1996 study by Drummond et al. indicated there was lack of consistency in the use of medicines that are combined in syringe drivers in palliative care (56). Different understanding and practices influence the use of syringe drivers; in some cases, availability may be a key factor in the lack of use. A follow-up study on those using this method would give a give a better evaluation of the uptake of this care provision in palliative care, especially at end of life.

Prescribing practices in palliative care, especially in developing and third world countries like Zimbabwe, may also be affected by lack of resources, the application of a health system paradigm from wealthy contexts (where current evidence comes from), and a universal fear of death and seeking of cure at all costs. The WHO, through the IAHPC, has developed an essential palliative care list which can be used as a model for countries to come up with their own national palliative care lists that meet local needs and take into account local resources, especially developing countries like Zimbabwe where there is limited availability of opioid analgesics and other palliative medications (37). Another area of concern is the use of combination drugs especially in chronic pain management for example a study done in South Africa (2016) by Truter "concluded that, first, generic substitution had an impact on prescribing patterns and, second, that more studies are needed to quantify combination analgesic and specifically meprobamate-containing analgesic prescribing" (57). Local national palliative care lists need support of local palliative care researches for their ongoing evaluation and renewal.

3. Rationale

Palliative care is about providing quality of life to people with life-threatening illnesses. For this to be achieved, a holistic approach is required in their care, including ensuring that the medicines/drugs needed are available and that prescribers follow best practices. This includes the excellent assessment and management of symptoms as envisaged in the WHO definition of palliative care, which in turn requires appropriate use of medication, that these drugs are available for use and that the supply is ensured. The palliative care symptom burden as raised by the patients or their care givers is essential evidence in advocating for palliative care. It is therefore important to research and review the local evidence of the current pharmacological management of palliative care symptoms in Zimbabwe, in order to establish a baseline from which the need for change can be evaluated. As palliative care is a new specialty, research coming from all countries, developed and developing, is an essential component in its provision and uptake by the patients and the health workers. The factors influencing the availability and uptake of palliative care drugs in each African country may overlap or be totally unique to each country. Results of this study and other similar research are intended to provide policy makers with an evidence base to support critical decisions to do with palliative care.

It is important to conduct this study to provide a baseline for the Zimbabwean context for comparison and development to improve policy and practice, and ultimately contribute to better patient care, the achievement of the sustainable development goals and universal health coverage throughout the trajectory of life.

3.1 Aim:

The aim of this study was to describe the prevalence of palliative care symptoms and the prescribing and administration patterns in oncology and haematology patients at PGH, as well as exploring the health workers' opinions on the pharmacological approach to these symptoms.

3.2 Objectives:

1. To review the palliative care symptoms in haematology and oncology patients at PGH.

2. To describe patterns of drug prescription and administration for palliative care symptoms at PGH.
3. To explore the opinions of health workers on palliative care drug availability and prescribing.

4. Methodology

4.1 Study Design

The study employed a mixed methods research (MMR) approach (58) using both qualitative and quantitative methods. Research methodology is developing and current evidence shows that combining different research methods gives an advantage of making use of the strengths of each method resulting in a stronger study. In this study, the qualitative aspect involved the use of a questionnaire which the health workers filled in, while the quantitative component of the study was a systematic document review methodology of patient records from 2017 until the required sample size was reached. Data collection was done in October 2018 and the most recent medical records to be accessed were of the year before (2017), since written records are scanned and stored into a system monitored by the medical records department. The department explained that records from the current year (2018) were still being uploaded hence they recommended use of 2017.

The patient records and health worker responses were considered adequate data sources to obtain the record of the pharmacological management of the palliative care symptom burden for the purposes of this project. Investigating the patient experience of the illness was beyond the scope of this study.

4.2 Study Sites

The study was conducted at PGH located in Harare. This is one of the main referral hospitals in Zimbabwe and serves as one of the few referral hospitals for haematology and oncology patients in the country. The haematology and oncology departments of PGH were used as the study sites, and the records department was used to get access to patient notes and information. The Zimbabwe national cancer registry is situated at the PGH complex and most of their data is obtained from PGH oncology wards and outpatient clinics (59).

4.3 Study Population

The study population included 12 doctors and 14 nurses working in the haematology and oncology departments and 2 pharmacists at PGH. All the participants agreed to take part in the study. Records of admitted (in-patients) haematology and oncology patients seen in 2017 provided the required sample for the quantitative analysis. If there were any re-admissions of the same patient encountered during the sequential extraction from admission books these were not taken. The rest of admissions of the same patient or other patients within the year were not included if falling outside the required sample selection criteria and after the required sample had been obtained. In line with the WHO definition and principles of palliative care which emphasizes that palliative care begins from the diagnosis of a life-threatening illness the study made the assumption that all the oncology and haematology patient records therefore would fit under palliative care and most of the diagnosis in these fields were assumed to be life-threatening (21).

Inclusion criteria:

All doctors, nurses and pharmacists working in haematology and oncology departments at PGH, who agreed to take part, regardless of their duration of service in these departments were included in the study. Only information extracted from admitted patient notes/records for 2017 was used.

Exclusion criteria:

All the doctors, nurses and pharmacists not working in the haematology and oncology departments were not included in the study. Haematology and oncology in-patient notes/records before and after 2017 were not used and readmissions of same patient were not used. Haematology and oncology out-patient records were not used.

4.4 Sampling

4.4.1 Patient records

For the purpose of this study, convenience sampling was conducted, reviewing the records of patients who were seen at PGH in 2017. Convenience sampling is a non-random sampling technique where members of the target population meet certain practical criteria (60).

The sample size required for the study was calculated as follows: the required sample size of the study participants was determined by *Dobson's* (1984) single population proportion formula using the assumptions of z, standardised normal distribution value for the 95% Confidence Interval, which is 1,96, p=0,80, an estimated proportion of cancer patients whose pain was effectively controlled by using the WHO recommended analgesic ladder guideline (Soares, 2005) (61) and taking Δ, the margin of error to be 5,0%, viz

$$n = \frac{z^2 \times p \times (1-p)}{\Delta^2}$$

$$= \frac{(1{,}96)^2 \times 0{,}80 \times (0{,}20)}{(0{,}05)^2}$$

$$= 246$$

A minimum sample size of 246 complete patient records was therefore required. The total number of 247 patient records was therefore obtained using convenience sampling, by means of accessing the required patient records using the hospital record system. This was done first by looking up successive admission hospital numbers up to 123 patients in the record book of ward C3 (haematology) and up to 124 from A6 (oncology) admitted in 2017 and then obtaining the records from the computer. The total number of records (247) required was reached within the period of January to March 2017.

4.4.2 Health workers

As mentioned earlier, convenience sampling is a non-random sampling technique where members of the target population meet certain practical criteria (60), such as patients in given wards, or health workers who operate within a given context. In this study, it was therefore

necessary to select health workers who possess the required criteria (working in the haematology and oncology departments and pharmacists at PGH), from among the rest of the health workers at the hospital. In qualitative studies, data analysis often takes place alongside data collection to allow questions to be refined and new avenues of inquiry to develop (62). During this process, the researcher conducts inductive thematic analysis to expose and explore categories, themes and subthemes as they emerged from the data. In the case of this study, the data relating to the health workers at the hospital was collected using a questionnaire and was halted once data saturation was reached.

4.5 Data Collection Tools and Processes

A questionnaire was used to collect information from the health workers. The questionnaire was administered in English to the health workers because English is the official language at work. With the permission of those in charge of the departments, information about the study was shared with small groups of doctors, nurses and pharmacists in both haematology and oncology departments. In the same meetings, the staff was informed that the researcher or research assistant would approach them with a consent form and questionnaire within the following week. It was anticipated that the questionnaire would take some time to complete, for which the participant was informed in the information sheet and one day was suggested as a helpful turnaround time. The anticipated turnaround time to get the questionnaire back seemed adequate for most of the research participants, who went through the information sheet in the morning when they reported for duty, and who were given the questionnaire at the same time. The participants then filled in the questionnaire during their tea or lunch break, submitting it to the researcher the following morning.

For convenience and quick identification of study participants, an oncology nurse working in the haematology ward was trained as the research assistant. The researcher elected to train an oncology nurse in the task, as their prior training as oncology nurses covered medical ethics and confidentiality. This knowledge and skill is transferable to medical research where autonomy and confidentiality are important. The research assistant's participation was voluntary and

there was no coercion. The researcher trained the research assistant, and supervised the survey distribution activities of the research assistant; the researcher then collated and filed the survey questionnaire results before analysis, ensuring that the assistant had conducted the process correctly before continuing with data analysis.

When the health workers were surveyed, the research team ensured that they understood the purpose and aims of the research study, and agreed to participate. Each participant was given an information sheet first explaining what the study was about, followed by signing the consent form and agreeing to the proposed submission timeline mentioned above of 24 hours. The researcher assigned each participant survey document a number in ascending order, starting from one, before the research assistant distributed the questionnaires amongst the participants. This was done so as to ensure the participants' confidentiality and avoid bias on the part of the researcher when analysing the survey results.

For the patient notes/records, the researcher arranged specific days and times with the records department to retrieve the required patient notes and fill in the necessary information in on the survey sheet. All the hand-written patient records at PGH are scanned and stored into a computerised system; this allows researchers with permission to log in with assistance from the records staff, conduct their research activities, and log out before they leave. Information was serially extracted from the patient records until the required sample size was reached, a process that took five working days for the researcher to complete, doing two hours every day. The survey areas for the quantitative part of the study using the patient records are listed at the end of Appendix 2, and the palliative care symptom list in Table 1 was used as a guide to identify the palliative care symptoms, however other symptoms not included on the table were also identified and analysed separately.

4.6 Data Analysis

The data obtained was transcribed by the researcher from the questionnaire responses into an electronic format for the purpose of analysis. Quantitative data was summarized in tables and

graphs, using short descriptions while the qualitative part was progressively analysed using inductive thematic analysis. A 16 gigabyte USB memory stick was used as an intermediate storage device from the computer, while every second or third day all the information was saved on a one terabyte external hard drive which was kept in a lockable drawer in order to keep the data secure and confidential. The audit from the patient records was entered into excel spreadsheets and analysed using the *Social Package For Social Sciences* (SPSS). Conducting the thematic analysis of the qualitative data was guided by the steps offered by Maguire M and Delahunt (2017) (63) and the researcher made a comprehensive critical analysis of the source data following Braun and Clarke (2006)'s description of thematic analysis (64) as listed below:

Step 1: Become familiar with the data,

Step 2: Generate initial codes,

Step 3: Search for themes,

Step 4: Review themes,

Step 5: Define themes,

Step 6: Write-up.

4.7 Validity and Reliability

Blanche et al in 2006 stated that "validity shows how sound the research findings are while reliability brings out how well the data can be reproduced" (65). A pilot study was used to test the viability of the questionnaire as a reliable and valid research instrument. As part of this trial, three senior health workers conveniently picked first from haematology, then from oncology and third from pharmacy department completed the questionnaire and gave the recommendation and suggestion to keep the questionnaire as open as possible. Based on these three responses, a few questions were refined or added, resulting in the final questionnaire which was later used to conduct the research. From this qualitative part of the study, the pilot showed that the health workers in the chosen departments were eager and provided the information; the fact that they took care of patients with palliative care symptoms in their work made the study more valid and reliable as they gave responses from their palliative care

experience. As for the patient records, the validity and reliability of the information that was extracted was tested by initially going through the first 10 oncology and haematology records comparing these data points with the disclosed objectives of the study. The researcher noted that the intentions of the study were coming out and hence continued with the rest of the records. In order to make sure the required health records were looked at during the survey, the researcher entered each new record using the hospital number and admission date into a note book and extracted responses to all the survey areas for each record before moving to the next.

4.8 Ethical Considerations

Permission to conduct the study was obtained from the two research ethics committees: UCT Human Research Ethics Committee (HREC) in line with the MPhil requirements and Medical Research Council of Zimbabwe (MRCZ), as the research was to be conducted in Zimbabwe. Copies of the permission to conduct the study from both UCT HREC and MRCZ are included at the end of the dissertation in the appendices. The clinical director of PGH and the heads of the respective departments were approached and given the proposal with the authorization from both research committees before commencing the study. For the questionnaire targeting health workers, informed consent was first obtained from the participants. Participants' confidentiality was maintained by using a coding system, where numbers were used instead of names. The same was applied to the patient records where instead of using patient names, the hospital numbers were used and coded with numbers in increasing order until the target number was reached. Participation in the study was voluntary and there was no barrier to participation or withdrawal. Participants were fully informed and were also informed that their participation was voluntary, and that they could withdraw at any time without explanation or prejudice.

4.9 Work Plan

The researcher had to meet the financial costs especially towards payment for the research assistant and the cost of research data collection stationery. The researcher sourced the

funding for the study from friends who support palliative care initiatives and from part-time work. The timeline of the study had to fit into the UCT MPhil in palliative care program.

4.10 Dissemination of Findings

The research findings will be shared with PGH, particularly the staff in the haematology, oncology and pharmacy departments, as they comprise the main participants. The study will also be disseminated to the Zimbabwean Ministry of Health taskforce that is dealing with the palliative care integration mandate. Conferences and seminars will be used as well to disseminate the findings whenever there is an opportunity to do so. Finally, with the supervisor's guidance an abstract of the study will be published in a recommended journal. A full article will be submitted for publication in a palliative care journal within one year of completion of the study.

5. Results

5.1 Questionnaire responses

Almost all of the health workers were senior cadres in their respective professions (doctors, nurses and pharmacists) evidenced by 10 of the doctors having more than 5 years' experience and 12 nurses with more than 5 years; the pharmacists' years of experience were not stated. The nurses and doctors were the majority of the health workers who participated in the study, with 50% and 43% respectively while pharmacists were the minority, at 7%. Table 2 summarizes the characteristics of health workers who filled in the questionnaire for the study.

Table 2 Characteristics of health workers who answered the questionnaire

Variables	Values
Health Workers	N=28
Doctors	
Less than 5 years' experience	2 (7.2%)
5 - 10 years' experience	4 (14.3%)
More than 10 years' experience	6 (21.4%)
Nurses	
Less than 5 years' experience	2 (7.2%)
5 - 10 years' experience	6 (21.4%)
More than 10 years' experience	6 (21.4%)
Pharmacists	2 (7.2%)

Six (21%) of the health workers, made up of two nurses and four doctors, said they use some form of symptom assessment method/tool in managing palliative care symptoms. The tools mentioned by these six participants included the pain scale, objective scoring, staging, a symptom assessment sheet and common toxicity criteria. No validated tools like the Integrated Palliative care Outcome Scale (IPOS) or Edmonton Symptom Assessment Scale (ESAS) were mentioned. The 27 palliative care symptoms listed on the questionnaire were selected by the health workers with differing frequencies. While some symptoms were commonly documented by most of the workers, other symptoms were only noted by few of the workers as shown in Table 3.

Table 3: Palliative care symptoms perceived by health workers in haematology and oncology departments

Symptom	Number of health workers who documented the symptom	Frequency %
Pain	28	100
Constipation	24	85.7
Vomiting	22	78.5
Nausea	20	71
Sleep problems	17	60.7
Anxiety	15	53.5
Weakness	14	50
Weight loss	13	46
Haemorrhage	12	42.8
Loose stool	12	42.8
Dyspnoea	12	42.8
Numbness/tingling	11	39
Low mood	11	39
Cough	10	35.7
Dry mouth	10	35.7
Tiredness	9	32
Urinary problems	9	32
Oedema	8	28.5
Neuropsychiatric	8	28.5
Hiccoughs	7	25
Dysphagia	6	21
Sweating	6	21
Dermatological	5	17.8

Taste change	5	17.8
Early satiety	5	17.8
Low mood	1	3.5
Fever	1	3.5

Fifteen health workers, made up of 11 doctors and four nurses out of the 28 health workers, responded that they prescribe palliative care medications; of these practitioners, nine said they consult the Essential Drug List of Zimbabwe (EDLIZ). Eleven participants responded that they use other references as a guide when prescribing for palliative care symptoms, with the following frequency:

- British National Formulary (BNF) – three health workers,
- UpToDate – two practitioners,
- National Comprehensive Cancer Network (NCCN) – two practitioners,
- Nursing drug guide – two practitioners, and
- Medscape – one practitioner.

In addition to this, one health worker said that he or she asked advice from senior colleagues as a method of informing prescribing for palliative care treatments.

Ten of the health workers, made up of two pharmacists and eight nurses responded that they dispense medication, and six nurses and 12 doctors responded that they do not dispense. Eight out of the ten who dispense medication highlighted that palliative care medications in their stock are inadequate, while one respondent said the stock is adequate.

Eighteen health workers, made up of the 10 who said they dispense drugs and eight others from those who said they do not dispense, responded to question 11 on the availability of essential palliative care drugs. The participants were required to rate the availability of certain essential drugs as never, sometimes or always available. Their response is summarized on figure 3 below showing oral morphine as the most available according to these health workers. Most

of the drugs' availability was rated as never or sometimes available by very few (1, 2 or 3) of the workers.

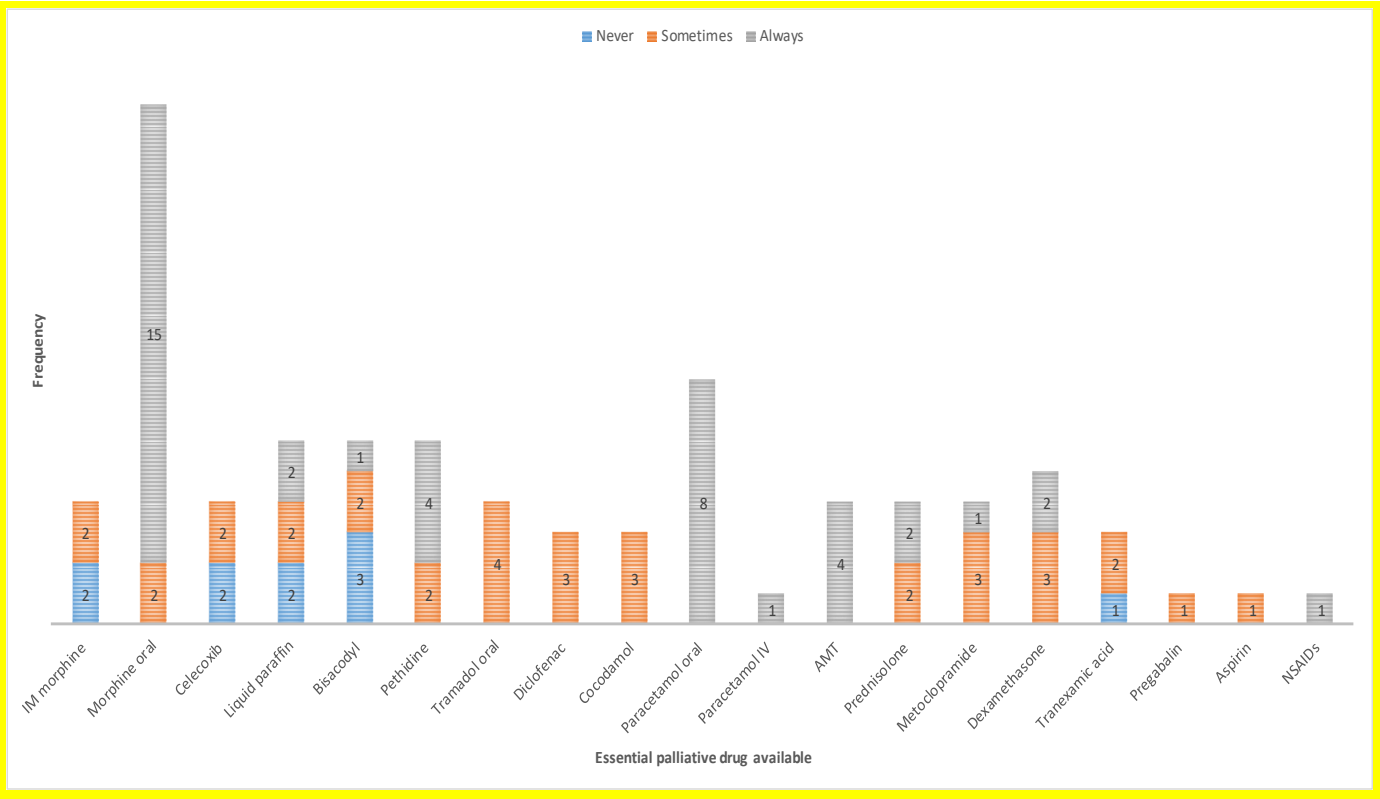


Figure 3 Availability of the drugs used by 18 health workers for palliative care symptoms

Key: IM-intramuscular, IV-intravenous, AMT-amitriptyline

Figure 4 below; shows the medications used for pain management by the health workers. For mild pain, 24 (85%) of the health workers use paracetamol, while a few also use other simple analgesics such as non-steroidal anti-inflammatory drugs (NSAIDs) and aspirin. The health workers listed different drugs for moderate pain which included tramadol and codeine and paracetamol combinations together with some co-analgesics such as amitriptyline. From the doctors and nurses 22 (78%) said that morphine was the drug of choice for severe pain and four (14%) reported that they use pethidine for severe pain in palliative care.

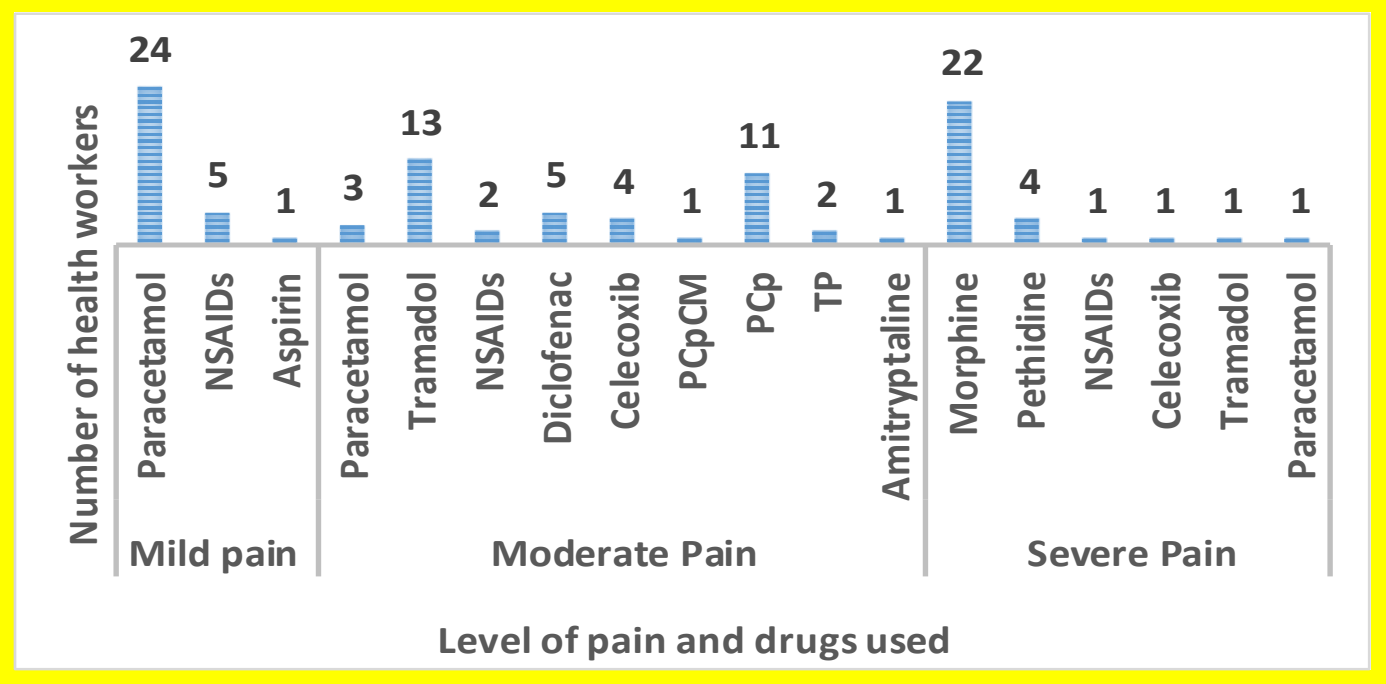


Figure 4: Palliative care drugs used for different pain levels by the health workers

Key: PCpCM: paracetamol/codeine phosphate/caffeine/meprobamate,

PCp:paracetamol/codeine phosphate, TP: tramadol/paracetamol

For the management of morphine side effects, 16 health workers (12 doctors and four nurses) reported constipation, which they treated using the following drugs according to frequency:

- bisacodyl – 13 health workers,
- senna – one participant,
- glycerine suppository – one participant,
- and liquid paraffin – 10 health workers.

Nausea and vomiting were highlighted by 10 participants (eight doctors and two nurses), and the practitioners used the following drugs to combat this symptom:

- metoclopramide – eight participants,
- ondansetron – nine participants, and
- polanestron– one health worker.

Three participants mentioned said dry mouth as a symptom, which they managed using ice cubes and plenty of fluids. One participant reported respiratory depression, for which they use oxygen, and one reported pruritis, for which they use chlorpheniramine.

Twenty-six of the health workers (12 doctors and 14 nurses) mentioned the following adjuvant/co-analgesic drugs for palliative care:

- dexamethasone -22,
- prednisolone – 21,
- amitriptyline – 21,
- gabapentin – 10,
- pregabalin – 11,
- carbamazepine -7,
- diclofenac, co-codamol, celecoxib and Indocin – 1.

Twenty health workers, noted that palliative care symptoms are not adequately controlled and the reasons for this was given in the subsequent questions which were qualitatively analysed below.

The health workers gave a long list of other palliative care symptoms besides pain, similar to the list provided earlier on Table 3. Only four of the listed symptoms were given corresponding drugs as illustrated on Table 4 below:

Table 4: Symptoms with corresponding drugs

Symptom	**Corresponding drugs**
Nausea and vomiting	Polanestron, chlorpromazine
Constipation	Bisacodyl, liquid paraffin
Bleeding	Tranexamic acid
Oedema/swelling	Frusemide, spironolactone

5.1.1 Inductive analysis of the health worker responses

The qualitative aspects of the health workers' responses are presented here using inductive thematic analysis. Questions 17,18,19 and 20 of the questionnaire are presented together in the analysis. The analysis was done using Braun and Clarke (2006)'s 6 pack (64) as alluded to earlier under methodology:

Step 1: Becoming familiar with the data.

The health workers who said the palliative care symptoms are inadequately controlled with the drugs used gave a number of reasons for it. The erratic supply of drugs and the fact that medications are not enough as well as the supply which is outweighed by demand are some of the reasons for the inadequacy of drugs. They also highlighted that shortage and high cost of drugs as well as cultural reasons, problems for which there are no medications and issues of compliance as reasons for inadequate control of Palliative Care (PC) symptoms. Unavailability of the ideal drug and the right route for the drugs contribute in not controlling PC symptoms. The constraints in prescribing palliative care drugs raised were mostly similar to the reasons given for the inadequate supply of drugs with some additions being the knowledge deficit among health workers on palliative care, compliance issues and few prescribers (mainly doctors). Recommendations and any other comments to do with pharmacological management of palliative care symptoms can be categorized into ensuring better supply of medications, education and training of health workers and patients and advocacy and policy issues. This data was analysed in combination drawing up similar threads and topics according to the steps below.

Step 2: Generating initial codes and Step 3: Search for themes

This process is shown in Table 5 below.

Table 5: Turning codes into themes

CODES	**THEMES**

Poor drug supply Shortage of drugs Drugs not accessible Drugs not available No alternative drugs	Availability of drugs Accessibility
Cost of drugs are high Poverty Financial constraints Provide free drugs	Affordability of drugs Provision of free drugs Advocacy
Cultural reasons affect taking of drugs Compliance issues on the patients Patients with issues not requiring medications Patient have their own perceptions Patients' distress and discomfort	Culture Compliance to medication Patient perceptions Distress
Lack of authority to prescribe morphine Nurses not prescribing drugs Laws that are in place for prescribing Pharmacists should be allowed to give medicines for palliative care symptoms. Standardize palliative care	Policy Advocacy
Educate health workers and patients on palliative care. PC drug formulary PC specialists are needed Provide ongoing courses Training MDTs	Education Training MDTs

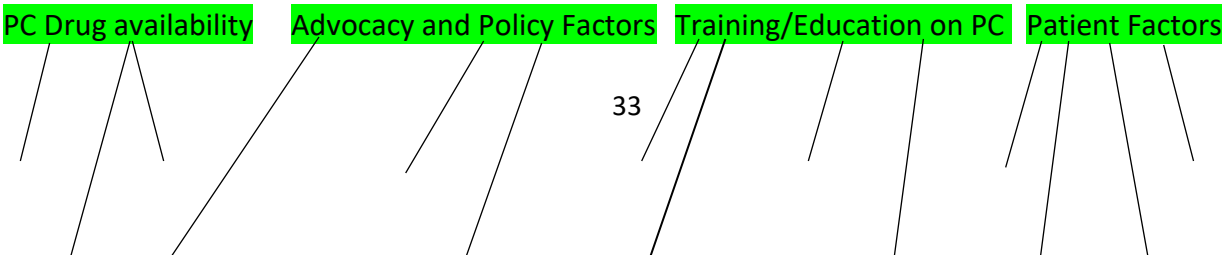
As shown on the table, the participants raised several issues to do with the pharmacological management of palliative care symptoms. Some of the highlights from the responses are: “the drugs are generally not available, so patients and families get prescriptions to look around and most do not afford to by the drugs anyway”, “this is a complex issue, even the patients’ understanding, compliance and other psychological issues contribute”, “prescribing is only done by doctors here, and sometimes there is no doctor nearby”, “it’s hard to implement something without appreciating its value first, there is need to educate doctors, nurses and pharmacists on palliative care first”.

Step 4: Reviewing themes

The themes obtained in Step 3 were reviewed using the initial responses of the health workers to check if there was something missing and confirm if the themes were really present in the data provided.

Step 5: Defining and naming themes

This is the final refinement of the themes and the aim is ‘to identify the essence of what each theme is about’ (65). A thematic map illustrating the relationships between the themes (66) is given in Figure 4 below. The main themes were obtained by following common threads in the health workers responses and main areas/topics under the overall theme.



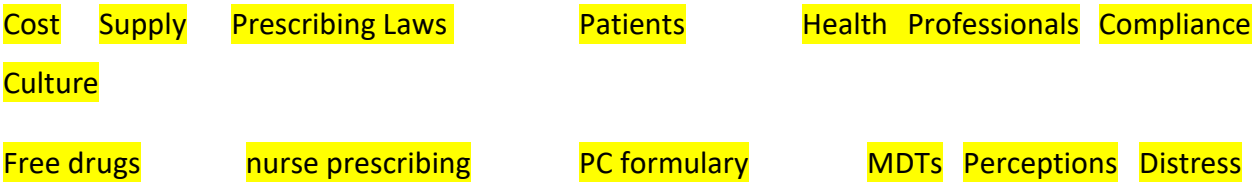


Figure 4: Thematic map with the final themes and how they interlink

Step 6: Write-up

This is continuation of the write-up started, now addresses each theme and provides conclusion to the thematic analysis showing how it has responded to the research objective on the opinions of health workers on the pharmacological management of palliative care symptoms.

5.1.2 Reviewing Key Themes

In this section, key themes that arose from the questionnaire analysis will be discussed in more detail.

Theme: Palliative care drug availability

The cost of the drugs, their supply and the need for free drugs are subthemes under the availability of drugs. This theme came up several times from the responses of the health workers; they may have expressed this theme differently, but the core idea was to do with drugs not being available. Some of the phrases from the health workers were: **"the supply of drugs is very erratic……patients cannot afford to buy the drugs as they are too expensive……the government should make palliative care drugs free."**

Theme: Policy factors

Suggestions to have nurses to prescribe palliative care drugs came out in the responses with some saying **"nurses should prescribe morphine"** and others saying **"nurses should prescribe where the doctors are not present".** Some responses which relate to policy issues highlighted the need to allow pharmacists to dispense drugs for chronic illnesses to patients with no prescriptions, with some saying pharmacists only supply analgesics to patients under palliative care.

Theme: Training and Education

The need for palliative care training in general for healthcare workers, especially nurses and doctors, was raised repeatedly with statements like **"doctors and nurses fear increasing medication for managing pain because of palliative care ignorance……train nurses and doctors on the importance of managing palliative care symptoms".** Health education of patients and their caregivers on palliative care was raised as well as the need for multi-disciplinary teams (MDTs) at hospitals to ensure palliative care provision. A palliative care drug formulary to guide the health workers was suggested by some of the respondents.

Theme: Patient Factors

Some of the responses were specifically directed towards the patients with statements like "patients are not compliant to the medications……due to cultural reasons some patients do not want to take their pain medications……patients have certain perceptions about medications". These and the need to educate patients and families was highlighted.

5.2 Findings from the patient medical records survey

A total of 247 patient records from haematology and oncology wards, of patients admitted in 2017 (January to March) were surveyed to extract the required information. The sample size corresponded with the statistical calculation described in the methods section.

Table 6: Demographic characteristics of patients whose records were reviewed (N = 247)

Sex	
Female	149 (60%)
Male	98 (40%)
Age group in years	
10-30	55 (22%)
31-50	99 (41%)

51-70	77 (31%)
71 +	16 (6%)
Median age (Q_1; Q_3)	46 (34; 60)
Mean	46.5

A range of oncology and haematology diagnoses were obtained from the patient records. Of note, cervical cancer had the highest frequency, at 19% of the records, followed by lymphoma at 15%. Besides having a cancer or haematology diagnosis, other comorbidities were also obtained in many of the patient records, with HIV/AIDS as the most common comorbidity, appearing in 43 (17%) of the records; the second-most common comorbidity was hypertension (11%).

Out of the 247 medical records reviewed, 52% of the records did not have any symptoms recorded on them as depicted in the pie chart – Figure 6.

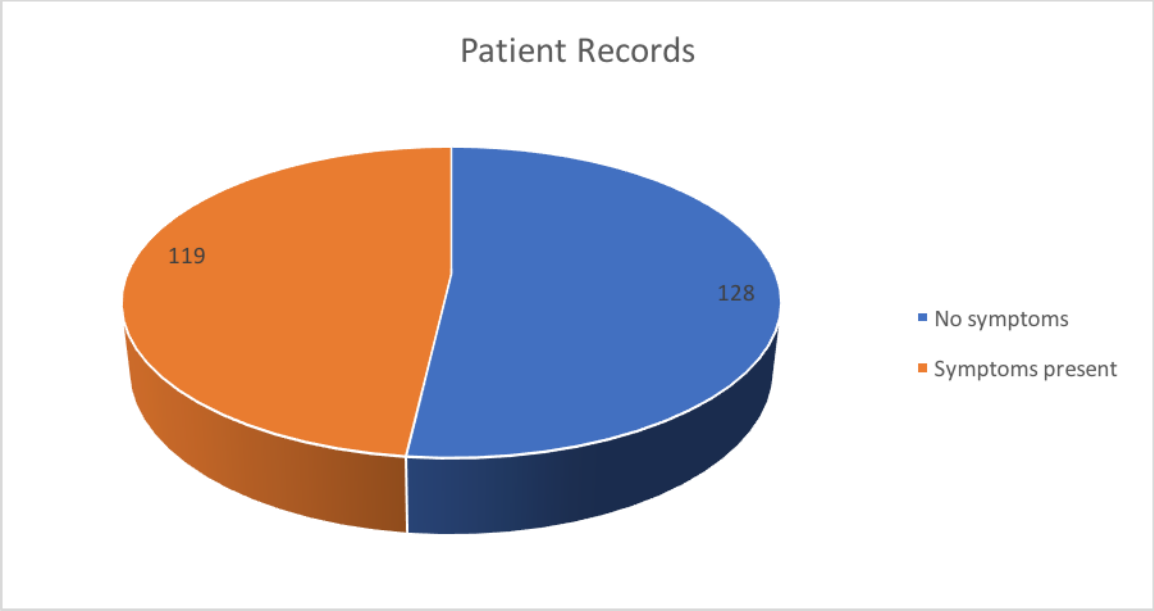


Figure 5: Number of patient records with and without palliative care symptoms recorded

The 52% of medical records that did not have any documented symptoms had no explanations to why there was no symptom documented.

Of the 119 medical records that had symptoms recorded, these varied; certain symptoms like pain were documented in many of the records while other symptoms were less frequently documented. Some of the records had more than one symptom recorded, and others had a single symptom noted. Table 7 below gives the summary of the symptoms obtained from the patient records research

Table 7: Palliative care symptoms from PGH oncology and haematology health records

Symptom	**Number of records with the symptom (N=119)**	**Frequency %**
Pain	106	89.1
Dyspnoea	62	52.1
Weakness	40	33.6
Oedema	30	25.2
Cough	24	20.2
Loss of appetite	22	18.5
Weight loss	20	16.8
Haemorrhage	19	16
Vomiting	15	12.6

Constipation	14	11.7
Sweating	9	7.6
Fever	8	6.7
Headache	7	5.9
Numbness, Neuropsychiatric (confusion), Dermatological (septic wounds), cachexia	6	5
Dysphagia, palpitations	4	3.3
Urinary problems, Loose stool	3	2.5
Nausea, Sleep problems (insomnia), dizziness, restlessness, pallor, secretions, visual problems, dehydration	2	1.7
Hearing problems, faecal incontinence	1	0.8

While the list from Potter et al. referenced in Table 1 was used to identify symptoms from the patient records, there were a few symptoms obtained from the records that are not on Table 1, which have been added to table 7 above, namely: loss of appetite, headache, cachexia, palpitations, dehydration, visual problems, secretions, pallor, restlessness, dizziness, hearing problems and faecal incontinence.

Drugs used for palliative care symptoms were prescribed in 130 (53%) medical records while 117 (47%) records did not have any of these drugs prescribed. Of the 130 records with palliative care drugs prescribed, some drugs were prescribed singly, while others were prescribed in combination with other drugs. Some drugs, like morphine and paracetamol, were prescribed more than others. Not all prescribed palliative care drugs were administered to the patients as shown in Table 8 below comparing what was prescribed and administered.

Table 8: Drugs prescribed for palliative care symptoms and administered

Drug prescribed	**Prescribed** **N=130**	**Administered**
Morphine	91	61
Paracetamol	38	37
Metoclopramide	34	9
Bisacodyl	34	15
Iron/hematinic preparation	30	20
Liquid paraffin	28	9
Tramadol	15	4
Tranexamic acid	14	4
Diclofenac	11	7
Dexamethasone	10	8
Prednisolone	9	6
Celecoxib	8	3
Amitriptyline	7	3
Aspirin	6	5
Omeprazole	6	5
Pregabalin	2	2
Indomethacin	1	1
Multivitamin	1	1
Ondansetron	1	1
Chlorpheniramine	1	0
Hyoscine butyl bromide	1	0

A drug written in the medical record was counted as a prescription, and which if administered would show on the drug chart that it has been administered by the presence of the nurse's

signature or initials and this study therefore concluded that the drug was both prescribed and administered. If the drug was not received, the drug chart had o/s (out of stock) or absent, hence the conclusion that the drug was not administered.

A general trend that patients do not get all the drugs prescribed was observed. Any documented drugs prescribed as 'whenever necessary' aimed at managing palliative care symptoms were included in the study. Drugs were prescribed on different days for the admission duration and there were no repeat prescriptions of the same drug within the admission period.

Of the 130 oncology and haematology records which had drugs prescribed, some had other drugs prescribed as well, but as they were not written on the drug administration chart, the researcher could not deduce whether they were administered or not. These other prescribed drugs are presented in the pie chart below.

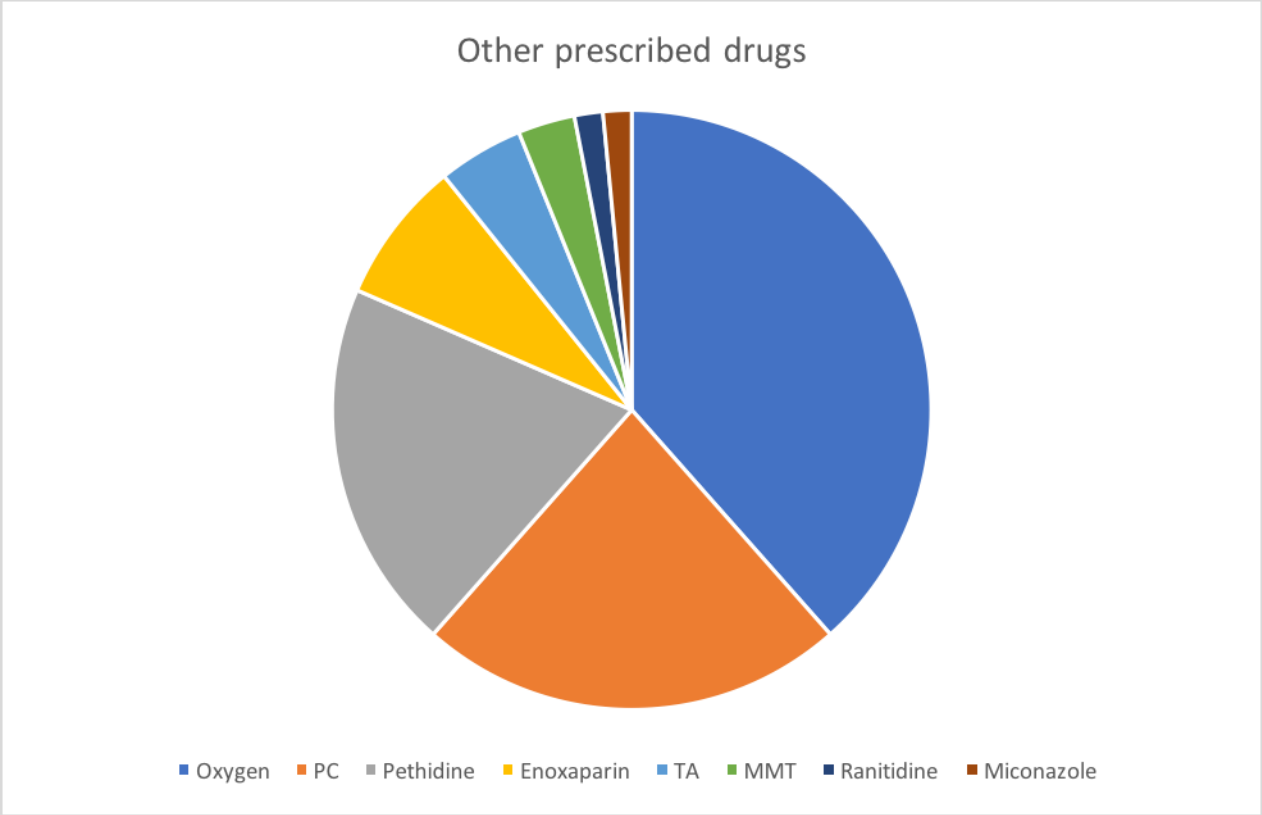


Figure 6: Other prescribed drugs not on the drug administration chart

Key: MMT-magnesium trisilicate, TA -Tramadol and acetaminophen, PC – Paracetamol and codeine phosphate

6. Discussion

The aim of this study was to describe the prevalence of palliative care symptoms in oncology and haematology patients at PGH, alongside the drugs and administrative processes for managing their symptoms. As discussed earlier, a mixed method approach involving both quantitative and qualitative methodology was chosen in this study to provide robust evidence of the pharmacological management of palliative care problems in the research context. Doyle et al showed that mixed methods provide a more complete and comprehensive picture of the research, which allows for generation of a hypothesis at the end which can be tested and followed up in future studies (67). In this study, in-depth information regarding the pharmacological management of palliative care symptoms was obtained and a hypothesis that clinician prescribing in Zimbabwe for palliative care symptoms is influenced by a number of factors, the 2 commonest being palliative care drug availability and palliative care knowledge of the prescribers was generated. A review and description of the management of palliative care symptoms was provided as well as exploration of the health workers' opinions. This section will review the findings and explore their implications on the policy and practice of managing palliative care symptoms at PGH.

6.1 Symptoms and their management

The main objective of this study was to look at the palliative care symptoms and how they are managed pharmacologically. This section will focus on the symptoms and how health care workers managed them. The researcher made the assumption that haematology and oncology problems fall under serious health related suffering which fits within the global consensus based palliative care definition through IAHPC recently published (68).

6.1.1 Documentation of symptoms

The first interesting aspect from reviewing the medical records was that the medical records survey showed that about half (52%) of the records did not have any symptoms documented. It is rare that oncology and haematology patients do not show any symptoms given the chronic nature of most of their illnesses, so this finding highlights potential areas for improvement in process, particularly in documentation of symptoms. There are several reasons that so many patient records did not have symptoms recorded, including early stage or curative patients being included in the cohort, or that these patients' symptoms were all controlled, or that potentially it was a result of unreliable documentation on the health workers' part. This finding can also be explained by the fact that the symptoms perceived as important by the doctor are the ones which will be reflected on the medical record which is one of the several reasons raised in an article by Strömgren, Grønvold, Pedersen, Olsen and Sjogren on the symptomatology of palliative care (69). The researcher can make inferences based on these records with no symptoms: perhaps the clinician was very busy and had no time to write down the findings, or as stated above the patient did not present with any symptoms but simply came for treatment of their chronic illness (70, 71). It is however not within this study's objectives to analyse the reasons for non-documentation of symptoms (whether for curative or chronic illnesses) on patient records, but this finding may still guide recommendations on improving documentation by the health workers. For example, if all the sections on the patient form are mandatory, the patient records would clearly show if no symptom was present, rather than that the health worker may not have noted it.

6.1.2 Symptoms and the drugs used to manage them

As mentioned in the results section, only four symptoms out of the 20 listed by health workers were listed with the drugs that were used to manage them (namely nausea and vomiting, constipation, bleeding and swelling), while the remaining sixteen symptoms were listed without recording a drug or treatment. This is striking, especially for research investigating the use of drugs to treat palliative care patients' symptoms. One possible reason that the health workers

did not list the medications used for many of the symptoms might mean that perhaps they did not find the symptoms significant; however, there may be other explanations which would require more research to elicit. The patient records showed that many patients did not get the drugs for the palliative care symptoms they presented with for example 91 patients had morphine prescribed and only 61 received the drug, this could be due to the reasons given by the health workers to do with challenges of access to free or reduced-price palliative care drugs to improve their use. There is a close link between the cost of the drugs and the number of patients who afford to get the drugs, which will be discussed shortly.

6.1.3 Pain as a key symptom

> **"Aaah morphine is what those who are about to die get, and some of the doctors I have seen before told me it is a dangerous drug and one should not get used to it".**
>
> ***Exploring a patient's opiophobia***

Pain emerged as the commonest palliative care symptom in this study, this corresponds with previous studies on palliative care symptomatology. From the patient records, pain was the commonest symptom observed, at 105 (48.8%) of the records, and the main drugs prescribed for pain were paracetamol and morphine but only 37 and 61 patients were administered these pain medicines respectively out of the 248 records which were reviewed. As common as the symptom of pain was, this has not been reflected in or positively influenced the availability of morphine as the drug of choice for moderate to severe pain in palliative care. This unfortunate scenario is clearly shown in this study where the prescribed and administered morphine was still very low as highlighted above. The 2009 report on the global distribution of pain medication, especially morphine, shows Africa having only 0.8% of the share (47) of global morphine consumption. This study in Zimbabwe affirms that less morphine is prescribed and administered than would reasonably be expected to be required, given the disease burden and

prevalence of symptoms, especially pain. Figure 8 below supports this unfortunate scenario especially for Africa. The findings in terms of pain control together with the concerns raised on drug availability (discussed below) by the health workers resonates with Pettus' statement in her article on reasons for drug policy reform (72). Pettus explained that "availability of controlled medicines must be commensurate with clinical need, with safe distribution and dispensing systems, to overcome the scandalously low consumption levels that for too long have been distorted by the war on drugs" (72) and the fact that opioid abuse affects availability (73). Issues to do with availability of palliative care drugs in general are further discussed later on in this write up looking commenting on the study findings.

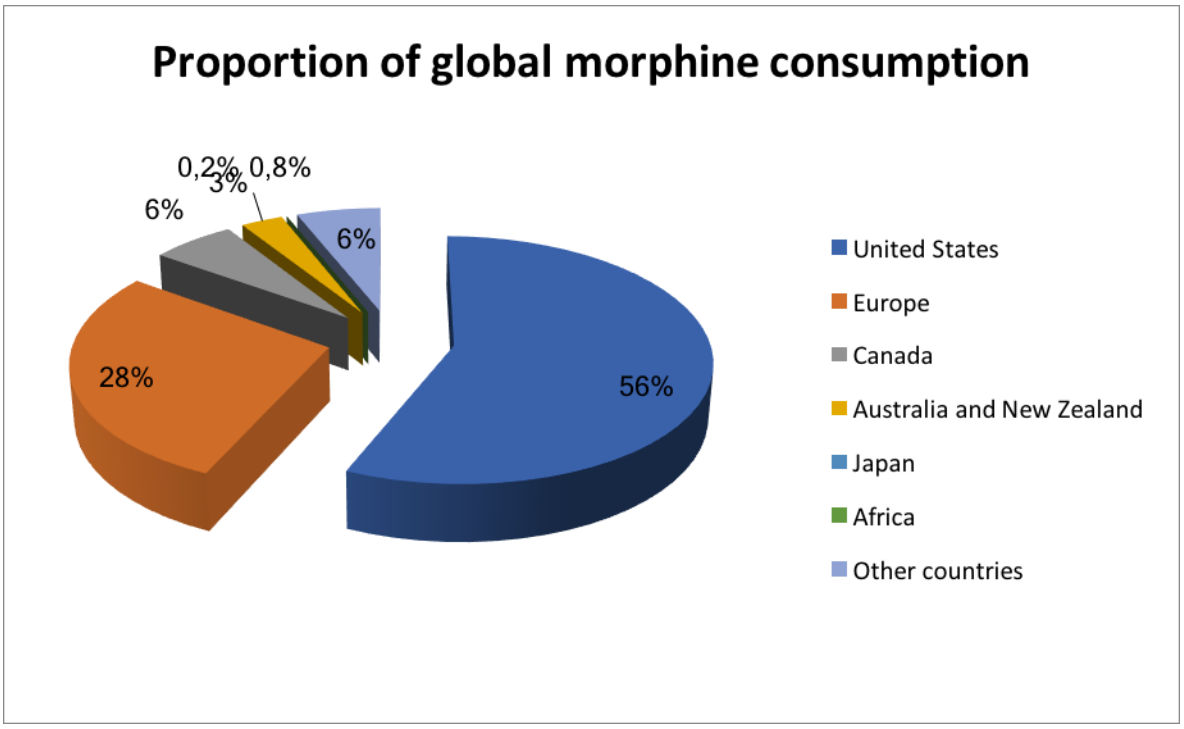


Figure 7: Worldwide distribution of morphine consumption in 2009 (Source: International Narcotics Control Board (47).

This study's findings on pain control showed the use of drugs like paracetamol, codeine phosphate, tramadol and morphine which are among the essential drugs for the different levels of pain. These analgesics used in pain management fall within the WHO analgesic step-ladder

and its components. WHO recommends palliative care analgesic approach of “by the mouth, by the clock, by the ladder and for the individual” (74) which was not explored here.

Severe pain (pain scale of 7-10) is one of the most common palliative care symptoms encountered by patients with life-threatening illnesses and the pharmacological management with opioids can be influenced by the patient, family and health care worker’s attitudes. Opiophobia from the patients and their families is a common encounter among palliative care practitioners and is made worse when other team members in healthcare share the sentiment of fear or mistrust of the medication. The reduced uptake in opioid analgesics in this study could as well have been due to opiophobia amongst other possible reasons.

In some cases, the patient records and health care workers indicated that severe pain in palliative care patients was managed using pethidine, which highlights the need for improved training especially on management of chronic pain associated with end-of-life care. In some cases, pethidine could have been prescribed for acute pain presentation; however, given the chronicity of most of the haematology and oncology conditions pethidine is inappropriate. Although EDLIZ says pethidine can be used for severe pain in patients who are allergic to morphine, there are many reasons why it should not be given in chronic pain; some of which are its short duration of action, no oral form, more anticholinergic effects, is neurotoxic and creates addiction (75). For example, sickle cell disease patients who often present in painful crisis, should have alternative pain management processes to avoid dependence on pethidine. This emphasizes the need to train the health care professionals in palliative care instead of just providing a list of medications (36). Pain control is therefore multifaceted, requiring the knowledge of the medications to be given by the health workers, the availability of the drugs and accessibility by the beneficiaries.

The use of combination drugs in pain management was reported by several health care workers and noted in the patient records. Pain control in palliative care using combination drugs like tramadol 37.5mg/paracetamol 325mg and acetaminophen 320mg/caffeine 32mg/ codeine phosphate 8mg/meprobamate 150mg was identified in both the health workers’ responses and

medical records. The South African study mentioned in the literature review showed that the use of combination drugs should not be used in palliative care due to the chronic nature of the symptoms especially pain which requires adjustments of doses on a regular basis (57). Combinations of simple analgesics certainly have a place in acute pain, especially nociceptive type but their use in chronic pain is discouraged, because of the frequency of drug interactions and adverse effects, particularly, paracetamol and codeine preparations as they are likely to lead to unwanted rebound effects such as sedation and impaired cognition (76).

6.1.4 Managing other distressing symptoms

Besides pain, there are other distressing palliative care symptoms as shown in the results section and these equally require proper pharmacological approach. Regarding patients with AIDS, there are now different findings due to the availability of ART and people living relatively healthier lives, however in the broader palliative care context cachexia is a syndrome which still presents with some of the distressing symptoms. One of the symptoms in the cachexia syndrome is weight loss, though its severity not quantified in this study it was mentioned by almost half of the health workers as one of the palliative care symptoms encountered and some of the patient records in the survey documented loss of weight. These findings affirm the fact that loss of weight is still a concern in palliative care. The number of patients documented in this study as having loss of weight was low in comparison to the total number of patient records. This symptom is often not listed when attending to patients even though some drugs have been seen to improve quality of life of cachexic patients. Corticosteroids for example dexamethasone 2-6 mg once a day have been shown to improve both anorexia and weakness in cancer patients (33).

The patient records survey and the responses given by the health workers show that the health workers understand the management of palliative care symptoms with drugs, which is demonstrated by the correlation of their responses and the study results with the WHO symptoms and palliative care medicines list. This study showed that there are local variations and attention to detail is important, including all symptoms identified in the local area, as well

as the common ones that are from Potter's list. The other symptoms identified were: palpitations, dizziness, dehydration, headache, loss of appetite, visual and hearing problems.

6.2 Understanding symptom assessment

The findings in this study show that most of the patients who require palliative care and pain relief do not get it for various reasons, which corresponds with the 2017 Lancet palliative care report for the developing countries. The results showed that there was a high palliative care symptom burden as elicited in the patient records and corresponding with the listed symptoms by the health workers. There was no systematic way of recording the symptoms, such as the use of an assessment tool; most of the patient records simply stated some symptom related to palliative care without reference to how that symptom was assessed. There was no standard/uniform format documented in the patient records for grading the pain or the other symptoms, although some health workers did mention some of the tools and resources they use. It is not certain therefore, whether and how health workers document their findings. These findings could be explained by the observation that in the "palliative care setting the patient population is often frail, has deteriorating health and has multiple symptoms" (77) which all influence getting the information from the patient. This supports the need for tools to act as a guide and to evaluate the care given and symptom management for the patient.

6.3Treatment and drug availability

Palliative care drug availability emerged as a major theme in the responses given by the health workers and drug availability is an important factor in palliative care symptom management, despite the lack of documentation about why patients did not get certain drugs. In the questionnaire, there was no guideline or list of drugs for the health workers to rate the availability (figure 3 on results), because this was intentionally left open to allow the respondents to report the drugs they have available on the ground, reducing predetermining the response after seeing a list. The availability of the essential medicines for palliative care is influenced by the supply chain and the cost of the drugs, a factor raised by the health workers. Palliative care is recognized as a basic human right, so it is important that it is treated

adequately. However, the patient records showed that in some cases, the drugs administered to patients were lower than what was prescribed as has been already discussed under pain management above. There are several reasons why admitted patients can miss getting their drugs, including stock insufficiency, patients declining, being unfit to take the medication or being absent during the medication time. However, from this study only the stock insufficiency was documented and this can be interpreted as an emphasis to the problems to do with the availability of the drugs.

Some of the prescribed drugs were out of stock, according to the drug chart and participants' responses. All the drugs in this study were either in short supply or not available as shown by the reduced figures of what the patients eventually received. This highlights the health workers' observation that drug supply is erratic, in short supply, very costly and not accessible to the patients. This shows that while the prescribers may do their part, the beneficiaries or the patients do not necessarily pharmacologically benefit from the care they are supposed to get in order to improve their quality of life due to factors to do with drug availability such as the supply and cost.

The cost of drugs was highlighted in the evidence as a big challenge for drug availability at the hospital, and some of the recommendations raised to improve palliative care symptom management includes advocating for free drugs for palliative care, especially considering control of the symptoms is a basic human right. In 2009 a study to evaluate children's palliative care service in Africa showed that the most valued service strengths were free drugs (78). By enabling access to free drugs, developing nations may be able to better look after their most vulnerable inhabitants, however the cost effectiveness of such an approach needs continuous evaluation, and perhaps they will need to come up with a way of covering the costs of this. Opting for free drug supply will eventually lead to a more controlled palliative care symptom burden and hence improved quality of life for the patients. The patient records clearly revealed the gap between expectations and reality in terms of the drugs the patients received, and we have considered possible reasons for this gap, including availability.

6.4 Policy, health workers and drug use

When considering the participants in the research study, it is worth noting that the doctors, nurses and other health workers were generally experienced practitioners. The fact that of the 26 health workers (doctors and nurses) who participated in the study, more than half, 18 (69%) had more than 5 years of work experience leads to a conclusion that the responses obtained were from people who have had enough exposure to patients (especially those with life-threatening illnesses) and therefore their responses when understanding their advocacy and use of drugs for treating palliative care symptoms need to be considered seriously. The thematic analysis of health worker responses on their opinions of the pharmacological management of palliative care symptoms revealed a similar trend with findings, specifically from the Lancet commission 2018, British journal of haematology 2011 and the Lancet oncology 2013 within LMIC (1-3, 6). This is an important finding in advocating and pushing for setting up the correct policies within the Zimbabwean context, as local findings correlate with similar evidence from other African situations. With all the supporting evidence from elsewhere and locally, the challenge is now to ensure the necessary action from all stakeholders concerned to implement the recommendations of these valued health workers.

Health workers emphasised the importance of policy, which plays a big role, from the cost of drugs or the need for engaging some nurses in prescribing for palliative care patients. Policies act as guiding and control standards for the practice. A qualitative study on the impact of nurse prescribing by Bradly and Nolan in UK noted that “nurse prescribing has the potential to improve service-user care, enhance collaboration and widen discussions about medicines” (79). Policy makers must also come up with other ways of bridging the gap between identifying the palliative care symptom and addressing it as priority, this may involve reviewing who can prescribe drugs for symptom management. In Zimbabwe, there has been provision for nurses to prescribe in certain areas of practice, for example midwives prescribing pethidine in labour; in the palliative care context, efforts are underway with the relevant bodies to have nurses prescribe morphine for palliative care patients. The suggestions from the health workers in this study on nurse prescribing for palliative care within the African context needs to be followed up

using comparative findings from regions that have already embarked on nurse prescribing for some time, especially the developed world.

Policy also influences how and when drugs are prescribed, as was indicated by participants of the study. Another area noted by the majority (57%) of the health workers was the use of references as an important guide in prescribing for palliative care symptoms. One of the sources mentioned was the EDLIZ. In support of providing reference lists to be used by prescribers, the national taskforce on palliative care in Zimbabwe is addressing the essential palliative care drug list inclusion into the EDLIZ so as to provide an easily accessible national guideline for the health workers. While the essential medicines concept was endorsed as way back as 1977 (80), the fact that patients still cannot get the essential medicines due to several factors is a cause for strong advocacy on behalf of the patients by the clinical team, the patients themselves and their families.

When considering lists of essential medications, policy and norms also play a role in the management of symptoms. This study made the assumption that the health workers working in haematology and oncology departments knew what was meant by palliative care medications as they take care of patients with life threatening illnesses, hence the questionnaire left it open, as discussed previously. However, the findings revealed a gap in the palliative care knowledge of the workers, and a checklist using the essential medicines for palliative care symptom management could have guided the responses. WHO defines “essential medicines as those which satisfy the primary health care needs of the population (81) and further states that twenty-one symptoms were identified as the most common in palliative care, with 33 medicines being included in the IAHPC List of Essential Medicines for Palliative Care” (82). Some of these were highlighted by the health workers in this study, but it is noteworthy that the lists of medications given by the health workers did not include all the drugs listed in the WHO essential drug list for palliative care (2013) or the EDLIZ (2015) chapter on pain and care of the terminally ill. It shows therefore that the WHO, EDLIZ and any other lists of recommended essential medications are guidelines that the clinicians use or may not use, but the reasoning for this was not explored in this study. However, the gap in the list of essential

palliative care medications in Zimbabwe's essential drug list is a noted area which is being addressed by the EDLIZ committee. A country's essential drug list is a useful guide especially in the primary health care setup where palliative care has to be implemented in the care of all the patients with chronic illnesses some of which pose serious challenges in the daily activities of the patients.

It is worth noting that this study was conducted at a tertiary institution in departments which were assumed to have more palliative care patients, but ultimately the research highlighted particular gaps in knowledge and practice; one can assume that at lower levels of care or in less specialized contexts, there is likely a similar picture. This needs to be proved by doing similar studies in clinics and other smaller health facilities. However, the point coming out here is the need to revisit policies which have a bearing on public health as they can positively or negatively have an impact on the population. If palliative care has to be provided at primary care level which is usually the first and last port of call for patients, it therefore calls for the need to have prescribers for essential medicines especially for morphine which is the recommended drug for moderate to severe pain in palliative care at all levels.

6.4.1 Policy and training for health professionals

Education and training of health professionals on palliative care symptoms and their management was highlighted by the participants as a prerequisite to improve palliative care. Ongoing training for health workers on history taking, physical examination and symptom assessment for palliative care patients is necessary as well as the drugs in use. Focussing on the pharmacological management of symptoms includes mentorship on the use of treatment protocols since these have proven effective interventions to promote rational prescribing (83). The WHO public health strategy, which was published after wide consultation and research includes education as one of the main strategies for the successful implementation of palliative care programs (84). A study by Reddy and colleagues concluded that "Haematology and Medical Oncology (HMO) fellows reported PC rotation improved their attitudes and knowledge in all PC domains" ((85), supporting the need for education and training in palliative care at all

levels. Health workers must therefore be trained to be confident to use the medication available to manage their patients' symptoms.

As indicated in the section of the discussion about the management of pain as a symptom, this research indicates the opportunity for improving quality of life for palliative care patients through improved training and understanding of global and local policy and recommendations. Therefore, there is need for ongoing update of health workers' knowledge in-order to keep up to the recommended guidelines for the recommended palliative care drugs for example exploring why combination drugs are discouraged in managing chronic pain. Education and training of the patient, family and health workers on the pharmacological approach of palliative care symptoms would help to increase demand for good symptom control as part of palliative care

6.5 Role of demographics: knock-on effect of improving palliative care symptom management

Considering the key focus of this study on symptoms and management, not all information within the patient records is within the scope of this study, but it may have some impact on the findings reported. For example, one note on demographics is that the female patient 149 (60%) predominance over the number of male patients 98 (40%) reviewed on records could most likely explain why cervical cancer was the predominant diagnosis, however these findings are not within the scope of this study and therefore will not be analysed or discussed further here. Some of the information discovered in the review of patient records, such as the age distribution and the patients' diagnoses, will be taken up by the researcher in further studies as they contribute to the knowledge base of palliative care.

The African context of this research is significant because of the role of symptom management for maintaining an active workforce struggling with life-threatening and life-limiting illnesses. In terms of the relevance of this research to other contexts, the patient demographics from this study has shown that in the African setting, palliative care is not only for the elderly as

evidenced by the big part of the records being for the 34-60-year age group. These findings correlate with a study which was done at a hospital in Malawi which also showed that the palliative care population is young, especially in patients with HIV related diagnoses (86). This is the working age population, and the amount of time given for work by those with life-threatening illnesses will be determined by the proper control of the palliative care symptoms they present with. This means that a good approach to managing palliative care symptoms has a knock-on effect on various aspects, including the country's economy.

6.6 Impact of findings in the Zimbabwean context

The impact of this study for Zimbabwe is that a holistic approach to palliative care in addressing the patient's needs should be emphasised as this not only engages the patient and the family but usually more than one health care professional (87). With the increasing need to integrate palliative care into the health care system in most countries, continuous evidence-based training of the recommended pharmacological approach for palliative care symptoms is necessary for health care workers at all levels in Zimbabwe. Good care for palliative care patients requires a holistic approach delivered by a multidisciplinary team, which was reflected and highlighted by the health workers in this study. The need for a multidisciplinary approach is felt more when palliative sedation is considered as this has strong patient and family factors which requires team deliberations to come to an agreement (54). This collaboration is often difficult as few doctors have had adequate palliative care training. Hence study brought out the need for multidisciplinary team approach in palliative care, this is however an area that perhaps needs further exploring within the Zimbabwean context putting into consideration issues which are specific for Zimbabwe.

This study showed that palliative care provision is not well integrated into the health care system of Zimbabwe, as evidenced by the findings on the pharmacological management of palliative care symptoms from one of the main tertiary hospitals in the country. The health workers emphasized some of the important gaps requiring attention in order to integrate palliative care, including drug availability, symptom assessment and recording and adequate

training for health workers. These key factors that fall under the public health strategy on palliative care were highlighted from the findings and resonate well with Lamas and Rosenbaum's statement in 2012 that "while the global burden of cancer and other non-communicable diseases grows, lack of funding remains an impediment to the dissemination of effective treatment" (88). Essential palliative care medicines are still not readily available, not accessible and not affordable to the public in Zimbabwe. Context-specific policies relating to the palliative care approach are required to improve access to essential medicines (89).

7. Limitations

1. The limitations of the study include the fact that it only focused on selected health workers and on patient records from the oncology and haematology patients of a selected hospital in Harare.
2. Questionnaire tool validity and reliability was compromised by the fact that the participants had to fill in the responses which were then further ascribed by the researcher, interpretation of what was exactly meant could have been somehow distorted given that certain words for example “method” would be interpreted differently, thereby coming up with conclusions not well supported by the data obtained.
3. Assumption that the participants would be going with the flow of questions linking them compromised the validity and reliability of some of the questions which were closed for example the question “are palliative care symptoms adequately controlled” and the response was a yes or no tick box, however this was followed up in the next question.
4. Patient records were sometimes incomplete, limiting the value of that record for data collection.
5. The scope of the study was limited due to the limited time and human resource capacity.

8. Recommendations

1. A similar study can be undertaken involving asking patients with life-threatening illnesses or their families, their feedback when given appropriate pharmacological interventions for their palliative care symptoms in order to assess their quality of life before and after.
2. The education and training committee for the Zimbabwe palliative care integration taskforce should note the gap in the knowledge observed in this study and highlight these areas in the ongoing in-service training, and the institutions of higher learning embarking on palliative care training should cover this within their curricula.
3. Issues of policy regarding availability of palliative care drugs at no cost or minimal cost to be taken on through relevant ministry of health officials and active advocacy by patients and health workers.
4. The IAHPC has developed the List of Essential Medicines for Palliative Care and it is available for use by all (82), this is an opportunity for all countries like Zimbabwe with supply problem to use.
5. Conduct a quantitative study to test the generated hypothesis that clinician prescribing in Zimbabwe for palliative care symptoms is influenced by a number of factors, the 2 commonest being palliative care drug availability and palliative care knowledge of the prescribers.
6. Follow up studies are important as they show the value of the previous study and promote uptake of the recommendations to inform good practice. In addition, this study was limited to a tertiary hospital context, and less-resourced settings may benefit from similar studies to explore if they suffer from similar gaps in knowledge and practice.
7. The guidelines operationalize the ideas and intentions therefore there is need for palliative care education and the whole PHS approach especially for prescribers.

9. Conclusion

This study focusses on the pharmacological management of palliative care symptoms in Africa and particularly in Zimbabwe by investigating practices and attitudes in one big institution in Harare. PGH is an important provider of treatment and quality of life for patients in Zimbabwe with life threatening illness.

The commonest symptom observed was pain and the findings showed that its management is generally aligned with the WHO guidelines, though with some variations, for example, the use of combination pain medications and other drugs not encouraged in patients with chronic pain. The study demonstrated a gap, however, in that doses of analgesic medication prescribed and administered were below the threshold of what would usually be required and possibly sub-therapeutic. This corresponds to experience and data from other African and LMIC countries.

Analysis of the responses of the health workers, which was supported in the patient record analysis identified a further gap in clinical practice which was a lack of use of symptom assessment tools to guide the comprehensive approach to care of patients with life threatening illness and a high symptom burden. Certain symptoms which may be amenable to management were not recorded or mentioned in the survey responses. The study opened up opportunities for future research in applying validated tools like IPOS or ESAS to the burden of symptoms.

Analysis of the responses of the health workers in the survey showed that nurse prescribing of some palliative care medications may address the pressing need for better symptom management in these patients.

Education and training of all health workers would be required to ensure comprehensive assessment using symptom assessment tools and safe prescription by all health workers, including nurse prescribing as suggested above. Advocacy plays an important role in palliative care provision, particularly to ensure the availability of palliative care medications and the

development of policy to support the required education for comprehensive palliative care, nurse prescription and contribute to the public health approach to palliative care provision.

This research project has explored the use and availability of palliative care medications and related factors providing evidence to improve practice, improve the quality of palliative care delivery and develop policy for the future implementation of these measures. This quality improvement would contribute to the attainment of the sustainable development goals.

10. Conflict of Interest

The author of this study declares no financial gain from doing this research besides meeting the requirements of the MPhil in Palliative medicine at UCT. Even though the researcher works at the study site there was no coercion or pressure brought on the participants.

11. Bibliography

1. Knaul FM, Farmer PE, Krakauer EL, De Lima L, Bhadelia A, Kwete XJ, et al. Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the Lancet Commission report. 2018;391(10128):1391-454.
2. Ddungu HJBjoh. Palliative care: what approaches are suitable in developing countries? 2011;154(6):728-35.
3. Harding R, Selman L, Powell RA, Namisango E, Downing J, Merriman A, et al. Research into palliative care in sub-Saharan Africa. 2013;14(4):e183-e8.
4. Powell RA, Mwangi-Powell FN, Radbruch L, Yamey G, Krakauer EL, Spence D, et al. Putting palliative care on the global health agenda. 2015;16(2):131-3.
5. Policies Hospaz: Hospice and Palliative care Association of Zimbabwe; 2020 [Available from: http//www.hospaz.co.zw/policies.
6. Luyirika EB, Namisango E, Garanganga E, Monjane L, Ginindza N, Madonsela G, et al. Best practices in developing a national palliative care policy in resource limited settings: lessons from five African countries. ecancermedicalscience. 2016;10.
7. WHO Definition Of Palliative Care.: WHO; [cited 2020 10 March]. Available from: https://www.who.int/cancer/palliative/definition/en/.
8. Watson MJWM, Lucas C, Hoy A, Wells J. Oxford Handbook of Palliative Medicine, 2nd ed. Oxford University Press, Oxford. Individualized measures of quality of life. 2009;56.
9. Mufunda J, Chatora R, Ndambakuwa Y, Nyarango P, Chifamba J, Kosia A, et al. Prevalence of noncommunicable diseases in Zimbabwe: results from analysis of data from the National Central Registry and Urban Survey. Ethnicity and Disease. 2006;16(3):718.
10. Magodoro IM, Esterhuizen TM, Chivese TJBrn. A cross-sectional, facility based study of comorbid non-communicable diseases among adults living with HIV infection in Zimbabwe. 2016;9(1):379.
11. Harding R, Higginson IJJTL. Palliative care in sub-Saharan Africa. 2005;365(9475):1971-7.
12. Danis MJTAJoB. Weighing the importance of palliation of symptoms for Ebola patients during the epidemic in west Africa. 2015;15(4):70-2.
13. Harding R, Powell RA, Kiyange F, Downing J, Mwangi-Powell FJJop, management s. Provision of pain-and symptom-relieving drugs for HIV/AIDS in sub-Saharan Africa. 2010;40(3):405-15.
14. Farrant L, Gwyther L, Dinat N, Mmoledi K, Hatta N, Harding RJSSAMJ. The prevalence and burden of pain and other symptoms among South Africans attending HAART clinics. 2012;102(6):499-500.
15. Fainsinger RL, Landman W, Hoskings M, Bruera EJJop, management s. Sedation for uncontrolled symptoms in a South African hospice. 1998;16(3):145-52.
16. Clark DJTlo. From margins to centre: a review of the history of palliative care in cancer. 2007;8(5):430-8.
17. Stjernswärd J, Foley KM, Ferris FDJJop, management s. Integrating palliative care into national policies. 2007;33(5):514-20.
18. De Lima LJJopc. IAHPC List of Essential Medicines for Palliative Care: summary of process for editors of pain and palliative care journals. 2006;22(4):300.
19. Potter J, Hami F, Bryan T, Quigley CJPm. Symptoms in 400 patients referred to palliative care services: prevalence and patterns. 2003;17(4):310-4.

20. Definition of Public Health University of Pittsburgh: Graduate School of Public Health; [cited 2020 31 March]. Available from: https://www.publichealth.pitt.edu/careers/what-is-public-health.
21. Sepúlveda C, Marlin A, Yoshida T, Ullrich AJJop, management s. Palliative care: the World Health Organization's global perspective. 2002;24(2):91-6.
22. Currow DC, Wheeler JL, Glare PA, Kaasa S, Abernethy APJJop, management s. A framework for generalizability in palliative care. 2009;37(3):373-86.
23. Singer PA, Bowman KWJBPc. Quality end-of-life care: a global perspective. 2002;1(1):1-10.
24. World Health Organization %J Geneva W. Cancer pain relief and palliative care: report of a WHO Expert Committee (Technical Bulletin 804, Publication 1100804). 1990.
25. Stjernswärd J, Foley KM, Ferris FDJJop, management s. The public health strategy for palliative care. 2007;33(5):486-93.
26. Organization WH. World health statistics 2016: monitoring health for the SDGs sustainable development goals: World Health Organization; 2016.
27. Hatchett L, Kaponda C, Chihana C, Chilemba E, Nyando M, Simwaka A, et al. Health-seeking patterns for AIDS in Malawi. 2004;16(7):827-33.
28. Hadler RA, Rosa WEJJop, management s. Distributive justice: an ethical priority in global palliative care. 2018;55(4):1237-40.
29. Strengthening of palliative care as a component of comprehensive care throughout the life course [cited 2020 3 April]. Available from: https://apps.who.int/medicinedocs/documents/s21454en/s21454en.pdf.
30. Zimcancerregistry.co.zw. [cited 2018 22 April]. Available from: http://www.zimcancerregistry.co.zw/about-us.html.
31. Fadul NA, Osta BE, Dalal S, Poulter VA, Bruera EJJopm. Comparison of symptom burden among patients referred to palliative care with hematologic malignancies versus those with solid tumors. 2008;11(3):422-7.
32. Harding R, Selman L, Agupio G, Dinat N, Downing J, Gwyther L, et al. The prevalence and burden of symptoms amongst cancer patients attending palliative care in two African countries. 2011;47(1):51-6.
33. Bruera E. ABC of palliative care: anorexia, cachexia, and nutrition. Bmj. 1997;315(7117):1219-22.
34. Kaasa S, Loge JH, Fayers P, Caraceni A, Strasser F, Hjermstad MJ, et al. Symptom assessment in palliative care: a need for international collaboration. Journal of clinical oncology. 2008;26(23):3867-73.
35. Norval DJSAMJ. Symptoms and sites of pain experienced by AIDS patients. 2004;94(6):450-4.
36. De Lima L, Krakauer EL, Lorenz K, Praill D, MacDonald N, Doyle DJJop, et al. Ensuring palliative medicine availability: the development of the IAHPC list of essential medicines for palliative care. 2007;33(5):521-6.
37. Who.int. 2020. [online] [Available from: https://www.who.int/selection_medicines/committees/expert/19/applications/PalliativeCare_8_A_R.pdf.
38. Masman AD, van Dijk M, Tibboel D, Baar FP, Mathôt RAJIjocp. Medication use during end-of-life care in a palliative care centre. 2015;37(5):767-75.
39. Star A, Boland JWJCM. Updates in palliative care–recent advancements in the pharmacological management of symptoms. 2018;18(1):11.
40. Mdpcz.co.zw. [cited 2020 21 April]. Available from: http://www.mdpcz.co.zw/wp-content/uploads/2018/10/EDLIZ.pdf.
41. Zeppetella. Prescribing in Palliative Care: Springer; 2012.
42. Ferrell B, Levy MH, Paice JJCjoon. Managing pain from advanced cancer in the palliative care setting. 2008;12(4).

43. Hølen JC, Hjermstad MJ, Loge JH, Fayers PM, Caraceni A, De Conno F, et al. Pain assessment tools: is the content appropriate for use in palliative care? Journal of pain and symptom management. 2006;32(6):567-80.
44. Tennant F, Tennant FJPPM. Editor's memo: the WHO pain treatment 3-step ladder. 2015;15:1-4.
45. Wrha.mb.ca. 2020 [cited 2020 7 June]. Available from: http://www.wrha.mb.ca/professionals/files/PDTip_AnalgesicLadder.pdf.
46. Vargas-Schaffer GJCFP. Is the WHO analgesic ladder still valid?: Twenty-four years of experience. 2010;56(6):514-7.
47. Organization WH. International Narcotics Control Board, United Nations Office on Drugs and Crime, editors. Guidelines for the Psychosocially Assisted Pharmacological Treatment of Opioid Dependence Geneva: World Health Organization. 2009:111.
48. Opiophobia: In Pallipedia. IAHPC.; 2019 [cited 2019 13 August]. Available from: https://pallipedia.org/opiophobia.
49. Khoo SB. Facts and fallacies in palliative care. Asia Pacific Family Medicine. 2003;2(3):143-7.
50. Grande G, Todd CJPM. Why are trials in palliative care so difficult? 2000;14(1):69-74.
51. Anderson BA, Kralik DJP, Care S. Palliative care at home: carers and medication management. 2008;6(4):349.
52. Sepulveda C, Habiyambere V, Amandua J, Borok M, Kikule E, Mudanga B, et al. Quality care at the end of life in Africa. 2003;327(7408):209-13.
53. Lewis ET, Combs A, Trafton JAJPM. Reasons for under-use of prescribed opioid medications by patients in pain. 2010;11(6):861-71.
54. Hauser K, Walsh D. Palliative sedation: welcome guidance on a controversial issue. SAGE Publications Sage UK: London, England; 2009.
55. Herndon CM, Nee D, Atayee RS, Craig DS, Lehn J, Moore PS, et al. ASHP guidelines on the pharmacist's role in palliative and hospice care. 2016;73(17):1351-67.
56. Drummond SH, Peterson GM, Galloway JG, Keefe PAJPm. National survey of drug use in palliative care. 1996;10(2):119-24.
57. Truter I. Prescribing of meprobamate-containing combination analgesics in South Africa. South African Family Practice. 2016;58(6).
58. Gelo O, Braakınann D, Benetkal G. Quantitative and Qualitative Research: Beyond.
59. Chokunonga E, Borok M, Chirenje Z, Nyakabau A, Parkin DJIjoc. Trends in the incidence of cancer in the black population of Harare, Zimbabwe 1991–2010. 2013;133(3):721-9.
60. Etikan I, Musa SA, Alkassim RSJAjot, statistics a. Comparison of convenience sampling and purposive sampling. 2016;5(1):1-4.
61. Soares LGLJAJoH, Medicine® P. Methadone for cancer pain: what have we learned from clinical studies? 2005;22(3):223-7.
62. Pope C, Ziebland S, Mays NJB. Analysing qualitative data. 2000;320(7227):114-6.
63. Maguire M, Delahunt BJAIJoHE. Doing a thematic analysis: A practical, step-by-step guide for learning and teaching scholars. 2017;9(3).
64. Braun V, Clarke VJQrip. Using thematic analysis in psychology. 2006;3(2):77-101.
65. Blanche MT, Blanche MJT, Durrheim K, Painter D. Research in practice: Applied methods for the social sciences: Juta and Company Ltd; 2006.
66. Caulfield J. How to Do Thematic Analysis | A Step-by-Step Guide & Examples [cited 2020 25 May]. Available from: https://www.scribbr.com/methodology/thematic-analysis/.
67. Doyle L, Brady A-M, Byrne GJJorin. An overview of mixed methods research. 2009;14(2):175-85.
68. Radbruch L, De Lima L, Knaul F, Wenk R, Ali Z, Bhatnaghar S, et al. Redefining Palliative Care–a New Consensus-based Definition. 2020.

69. Strömgren AS, Grønvold M, Pedersen L, Olsen AK, Sjogren PJEJoC. Symptomatology of cancer patients in palliative care: content validation of self-assessment questionnaires against medical records. 2002;38(6):788-94.
70. Rowley RJFpm. practicing without paper charts: One clinic's experience. 2005;12(2):37.
71. Tsai J, Bond GJIJfQiHC. A comparison of electronic records to paper records in mental health centers. 2008;20(2):136-43.
72. Pettus K. Reasons for drug policy reform: millions of people are left with untreated pain. BMJ. 2017;356:j309.
73. Manjiani D, Paul DB, Kunnumpurath S, Kaye AD, Vadivelu N. Availability and utilization of opioids for pain management: global issues. Ochsner Journal. 2014;14(2):208-15.
74. Staff WHO, Organization WH. Cancer pain relief: with a guide to opioid availability: World Health Organization; 1996.
75. Auret K, Schug SAJD, aging. Underutilisation of opioids in elderly patients with chronic pain. 2005;22(8):641-54.
76. Mielke J. Medications for chronic pain: practical review. 2009.
77. Moro C, Brunelli C, Miccinesi G, Fallai M, Morino P, Piazza M, et al. Edmonton symptom assessment scale: Italian validation in two palliative care settings. Supportive care in cancer. 2006;14(1):30-7.
78. Amery JM, Rose CJ, Holmes J, Nguyen J, Byarugaba C. The beginnings of children's palliative care in Africa: Evaluation of a children's palliative care service in Africa. Journal of palliative medicine. 2009;12(11):1015-21.
79. Bradley E, Nolan P. Impact of nurse prescribing: a qualitative study. Journal of advanced nursing. 2007;59(2):120-8.
80. Hogerzeil HV. Essential medicines and human rights: what can they learn from each other? Bulletin of the World Health Organization. 2006;84:371-5.
81. Organization WH. WHO model list of essential medicines: 18th list, April 2013. 2013.
82. De Lima L, Krakauer EL, Lorenz K, Praill D, MacDonald N, Doyle D. Ensuring palliative medicine availability: the development of the IAHPC list of essential medicines for palliative care. Journal of pain and symptom management. 2007;33(5):521-6.
83. Hogerzeil HV. Promoting rational prescribing: an international perspective. British journal of clinical pharmacology. 1995;39(1):1-6.
84. Stjernswärd J, Foley KM, Ferris FD. The public health strategy for palliative care. Journal of pain and symptom management. 2007;33(5):486-93.
85. Reddy SK, Tanco K, Yennu S, Liu DD, Williams JL, Wolff R, et al. Integration of a Mandatory Palliative Care Education Into Hematology-Oncology Fellowship Training in a Comprehensive Cancer Center: A Survey of Hematology Oncology Fellows. Journal of oncology practice. 2019:JOP. 19.00056.
86. Tapsfield JB, Bates MJ. Hospital based palliative care in sub-Saharan Africa; a six month review from Malawi. BMC palliative care. 2011;10(1):12.
87. Graham F, Clark D. WHO definition of palliative care. Medicine. 2008;2(36):64-6.
88. Lamas D, Rosenbaum L. Painful inequities—palliative care in developing countries. New England Journal of Medicine. 2012;366(3):199-201.
89. Mendis S, Fukino K, Cameron A, Laing R, Filipe Jr A, Khatib O, et al. The availability and affordability of selected essential medicines for chronic diseases in six low-and middle-income countries. Bulletin of the world health organization. 2007;85:279-88.

12. Appendices

Appendix 1: Information Sheet

Title of the research: The pharmacological management of palliative care symptoms in hematology and oncology patients at Parirenyatwa group of hospitals (PGH) in Harare Zimbabwe.

Introduction

Thank you for giving your time to hear about this study. This information sheet tells you about the study that you may wish to take part in. You may have some further questions to help you decide whether you want to take part. You can ask any further questions from the researcher, supervisor or co-supervisor using the telephone numbers at the end.

Thank you for thinking about whether you want to take part. Please take your time to make a decision.

The study findings will be used to support the Zimbabwe ministry of health's current efforts to integrate Palliative Care into the country's health system delivery.

What is the purpose of the study?

The aim of this study is to determine the drugs used in the management of palliative care symptoms in hematology and oncology patients at PGH thereby identifying gaps or areas of strength using the WHO essential drug list for palliative care.

Do I have to take part?

No, you do not have to take part. If you do agree to take part, you are free to withdraw from answering the questionnaire at any time without giving any reason. If you do agree to take part, you will be asked to sign a consent form, which shows that you have agreed to do so. You can take some time to think about whether you would like to take part.

How is the study conducted?

After you have read through this information sheet and signed your consent to take part in the study you will get a questionnaire from the research assistant which you have to fill in the responses and give back to the research assistant. Further information will be obtained from patient records at PGH.

What do we expect from you?

You are asked to fill in the questionnaire given to you. This will take about 10minutes of your time. Your participation is voluntary and you can decline to answer certain questions or end your participation at will.

What happens if you do not wish to participate in this study?

Participation in this study is voluntary; therefore, if you decide not to participate you can withdraw without signing anything else. You are not obliged to explain why you do not want to participate but if you want to explain why you may do so.

What happens to your data?

The questionnaires will use number codes, so your name will not appear. The information on the questionnaires will be transferred into database which will not trace any of the information to you but will be anonymous.

Is there anything else you want to know?

For any questions or clarifications about this study you can contact the researcher and/or co-supervisor on the details given below. Kind regards,

Researcher: Agnes Chipo Tererai, +263782321202, email: atererai@gmail.com

Supervisor: Dr Alan Barnard, UCT, +27835642939

Co-supervisor: Dr N Tsikai, UZ, +263772275888

If you have any questions about your human rights or any ethical issues please contact:

UCT Research Ethics Committee:

Mrs. Lamees Emjedi Research Ethics Committee E 52 Room 24, Old Main Building, Groote Schuur Hospital, Observatory Telephone: 021 406 6338

Consent form

1. I confirm that I have read and understand the information sheet and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and I am free to withdraw at any time, without giving a reason, without my care being affected.

3. I agree to take part in the above study.

Name _____

Signature _____ Date _____

Researcher: Signature _____ Date: _____

Witness: Name

(from clinical team or family member)

Signature _____ Date: _____

Appendix 2: Questionnaire for health workers and Patient records survey

Topic: The pharmacological management of palliative care symptoms in hematology and oncology patients at Parirenyatwa group of hospitals (PGH) in Harare Zimbabwe

Please fill in all that applies to your level!

1. What is your profession, tick applicable

☐Specialist Dr ☐Senior Doctor ☐Junior Doctor ☐Registrar (MMed)

☐Senior Nurse ☐Oncology Nurse ☐Student Nurse ☐Pharmacist

☐Other……..

2. How many years have you been practicing: Tick applicable

☐<5years ☐5-10years ☐ >10years

3. Do you use a symptom assessment method/tool? ☐ YES ☐NO
4. If Yes to above, which method/tool do you use?.....
5. Number the Palliative care symptoms you manage (use list below or add your own) according to the most common presenting starting from 1 as most common

☐Pain	☐Anorexia	☐ Constipation
☐Weakness	☐Dyspnea	☐ Nausea
☐Neuropsychiatric	☐Tiredness	☐ Weight Loss
☐Low mood	☐Vomiting	☐ Dry Mouth
☐Cough	☐Dermatological	☐ Urinary
☐Anxiety	☐Edema	☐ Sleep problems
☐Loose stool	☐Dyspepsia	☐ Numbness/tingling
☐Dysphagia	☐Hemorrhage	☐ Early satiety
☐Sweating	☐Hiccoughs	☐ Taste Change

☐Other……

6. Do you prescribe PC medications: YES ☐ NO ☐
7. Do you consult EDLIZ when prescribing PC drugs: ☐ YES ☐ NO

8. What other sources do you consult when prescribing PC drugs……..

9. Do you dispense medications/drugs YES☐ NO ☐

10. If yes to 9 above, how do you rate your Palliative Care drug stocks? Tick applicable:

☐ Inadequate ☐ Adequate

11. Please list the essential palliative care drugs in your stocks under the descriptions below:

Never	**Sometimes**	**Always**
……	……	……
……	……	……
……	……	……
……	……	……
……	……	……
……	……	……
……	……	……

12. For Pain list the drugs you use?

Level of Pain	**Drugs used**
Mild Pain	**……**
Moderate Pain	**……**
Severe Pain	**……**

13. List the drugs you use for morphine side effects

Morphine Side Effect	**Drugs**
……	……
……	……
……	……
……	……
……	……

14. Tick Adjuvant/co-analgesic drugs in Palliative Care used at your department

Drug

☐ Prednisolone ☐ Carbamazepine

☐ Dexamethasone

☐ Amitriptyline

☐ Gabapentin

☐ Pregabalin

☐ Other…….

15. Besides pain please list other 5 common PC symptoms you manage/see and the drugs you use?

PC Symptom **Drugs Used**

……. ……..

……. ……..

……. ……..

……. ……..

……. ……

……. ……..

……. ……..

16. From your experience, are palliative care symptoms adequately controlled for your patients in terms of drugs used? ☐ Yes ☐ No

17. If you answered No above, explain why they are not adequately controlled?

……

……

……

18. List/Describe 2 or 3 constraints you face in prescribing or dispensing drugs for palliative care symptoms?

1……

……

2……

……

3……

……..

19. Give 2 or 3 recommendations to improve pharmacological management of palliative care symptoms in your setting.

    1……

    ……

    2……

    ……..

    3……

    ……

20. Please write below any other comments you may have concerning pharmacological management of Palliative Care symptoms:

    1……

    2……

    3……

    4……

    5……

    6……

    7……

Patient records survey topics

1. Age
2. Sex
3. Diagnosis
4. Palliative care symptoms documented
5. Palliative care drugs prescribed
6. Palliative care drugs administered
7. Any other drug used for PC symptoms.

Appendix 3: UCT HREC Approval

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room E53-46 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6626
Email: shuretta.thomas@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

20 August 2018

HREC REF: 528/2018

Dr Alan Barnard
Public Health & Family Medicine
Entrance 5, level 2
Falmouth Building

Dear Dr Barnard

PROJECT TITLE: THE PHARMACOLOGICAL MANAGEMENT OF PALLIATIVE CARE SYMPTOMS FOR HEMATOLOGY AND ONCOLOGY PATIENTS AT PARIRENYATWAGROUP OF HOSPITALS, HARARE, ZIMBABWE (MPhil Candidate - Ms A. C. Tereral)

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study subject to approval from the Harare REC.

Approval is granted for one year until the 30 August 2019.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

Please quote the HREC REF in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

The HREC acknowledge that the student Agnes Chipo Tereral will also be involved in this study.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE
Federal Wide Assurance Number: FWA00001637.

HREC 528/2018

Appendix 4: MRCZ approval

Telephone: 791792/791193
Telefax: (263) - 4 - 790715
E-mail: mrcz@mrcz.org.zw
Website: http://www.mrcz.org.zw

Medical Research Council of Zimbabwe
Josiah Tongogara / Mazoe Street
P. O. Box CY 573
Causeway
Harare

APPROVAL LETTER

REF: MRCZ/B/1571 **21, September, 2018**

Dr.Agnes Chipo Tererai
Box EH 93
Emerald Hill
Harare

RE: PHARMACOLOGICAL MANAGEMENT OF PALLIATIVE CARE SYMPTOMS IN HEMATOLOGY AND ONCOLOGY PATIENTS

Thank you for the above titled proposal that you submitted to the Medical Research Council of Zimbabwe (MRCZ) for review. Please be advised that the Medical Research Council of Zimbabwe has **reviewed** and **approved** your application to conduct the above titled study. This is based on the following documents that were submitted to the MRCZ for review:

a) Study proposal
b) Consent Forms

APPROVAL NUMBER **: MRCZ/B/1571**
This number should be used on all correspondence, consent forms and documents as appropriate.

- **APPROVAL DATE** **: 21 September, 2018**
- **TYPE OF MEETING** **: Expedited**
- **EXPIRATION DATE** **: 20 September, 2019**
  After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the MRCZ Offices should be submitted one month before the expiration date for continuing review.
- **SERIOUS ADVERSE EVENT REPORTING**: All serious problems having to do with subject safety must be reported to the Institutional Ethical Review Committee (IERC) as well as the MRCZ within 3 working days using standard forms obtainable from the MRCZ Offices.
- **MODIFICATIONS**: Prior MRCZ and IERC approval using standard forms obtainable from the MRCZ Offices is required before implementing any changes in the Protocol (including changes in the consent documents).
- **TERMINATION OF STUDY**: On termination of a study, a report has to be submitted to the MRCZ using standard forms obtainable from the MRCZ Offices.
- **QUESTIONS**: Please contact the MRCZ on Telephone No. (04) 791792, 791193 or by e-mail o.

Other

- Please be reminded to send in copies of your research results for our records as well as for Health Research Database.
- You're also encouraged to submit electronic copies of your publications in peer-reviewed journals that may emanate from this study.

Yours Faithfully

.....

MRCZ SECRETARIAT
FOR CHAIRPERSON
MEDICAL RESEARCH COUNCIL OF ZIMBABWE

MEDICAL RESEARCH COUNCIL OF ZIMBABWE
2018 -09- 2 1
APPROVED
P.O. BOX CY 573 CAUSEWAY, HARARE

PROMOTING THE ETHICAL CONDUCT OF HEALTH RESEARCH